

Comparison of quality of life and health behaviors between
melanoma survivors and controls

A Dissertation
SUBMITTED TO THE FACULTY OF
UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

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January 2016

Acknowledgements

This dissertation was completed with guidance from and the contributions of numerous individuals. First, I thank my dissertation committee, Drs. Kristin Anderson, Anne Blaes and Heather Nelson, for their review and feedback on this work and more importantly their overall mentorship. A special thank you to my adviser, Dr. DeAnn Lazovich, who provided me with unrelenting support and numerous opportunities for hands-on research experience. I have learned more in the past five years than I ever could have imagined and feel prepared to start my own research path; for that I will be forever grateful.

The work described in this dissertation involved primary data collection which would not have been possible without the tireless efforts of Lori Strayer and Leah Engleman. Thank you also to family and friends who volunteered their valuable time to complete various administrative tasks – I never could have sent almost 8,000 pieces of mail without you.

I am appreciative of the funding support Dr. Lazovich and I received to complete this project. The studies herein were supported by the Masonic Cancer Center of the University of Minnesota's Internal Grants Program, along with NIH grants P30 CA77598 and UL1TR000114, and the J.B. Hawley Student Research Award through the Division of Epidemiology and Community Health, University of Minnesota.

I would like to express my appreciation to all of the melanoma survivors who participated in these studies. The experiences shared remind me of the human lives behind a cancer diagnosis and fueled my passion for survivorship issues.

I am indebted to the numerous mentors I have had over the past decade who dedicated their time and expertise to cultivate my skills and guide my career. Special thanks to Drs. Chap Le, Melissa Geller, and Dorothy Hatsukami, who each supported my pursuit of this degree and provided numerous opportunities to further build my research career.

I am grateful for the other Ph.D. trainees who have travelled this journey with me, in particular Amber Fyfe-Johnson. Many obstacles in this program could not have been overcome without her.

Most importantly, the completion of this program and dissertation was possible because of the unending love and support of my husband, Nick. He is my rock and has contributed to my success on a daily basis.

Dedication

This dissertation is dedicated in memory of my brother Phil Isaksson. When we were kids he would brag about his nerdy older sister, saying she was so smart she was going to cure cancer someday. I would not go that far, however, I plan to devote my career to improving the lives of people diagnosed with cancer.

Abstract

Unlike most cancer types, melanoma incidence has been increasing over the past 30 years in the United States. The unique characteristics of melanoma argue for research that captures the specific issues faced by melanoma survivors. Studies of long-term melanoma survivors are lacking, and the survivorship research to date has been limited by the inability to make comparisons with a population control group. The goal of this dissertation was to document the long-term effects of a melanoma diagnosis and treatment on survivors and compare their quality of life and health behaviors with population controls. First, a series of focus groups were conducted to describe the breadth of experiences among melanoma survivors, focusing on the experience at diagnosis, ongoing physical, emotional and social concerns, and behavioral changes since diagnosis (Manuscript 1). Based on these data, a comprehensive questionnaire to address the quality of life issues faced by melanoma survivors was designed and tested. Finally a cross-sectional study of melanoma survivors and population controls was conducted. The goal was to collect data to evaluate the impact of melanoma on long-term survivorship focusing on quality of life (Manuscript 2) and sun exposure and protection behaviors (Manuscript 3). A total of 592 melanoma survivors and 518 controls completed the survey. Results indicate that long-term survivors of melanoma reported similar general physical and emotional quality of life as controls. In addition, while they generally reported greater use of sun protection behaviors than controls, a significant subgroup experienced sunburn in the past year, putting them at elevated risk for future melanomas. The data presented in this dissertation suggest that long-term melanoma survivors

reported similar quality of life as controls, though opportunities exist to improve their sun exposure and protection behaviors.

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1 Background and Purpose

1.1 Introduction

As of January 1, 2014, an estimated 14.5 million cancer survivors were living in the United States.¹ The American Cancer Society defines a cancer survivor as “any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life.” In practice, however, survivorship is generally considered as the period following treatment. Improvements in cancer detection, treatments, follow-up care, and screening have increased cancer survival rates. This has led, however, to more survivors living long enough to experience long-term and late effects of cancer and cancer therapy and development of secondary malignancies.²

The impact of cancer on an individual depends on many factors – age, comorbidities, diagnosis (disease, stage, location), and type and intensity of treatment.³ Unfortunately, few cancer treatments are considered benign; surgery, chemotherapy, and/or radiation are often the mainstay and are known to cause numerous short- and long-term physical and psychological side effects.² For this reason, many clinical trials of new treatments include measures of treatment side effects and quality of life in addition to the primary outcomes of overall and disease-free survival.

In the past decade a number of studies were conducted to ascertain information on cancer survivors.⁴ Results to date indicate that most cancer survivors describe good general health, however some face long-term physical, social, and emotional concerns, including anxiety related to fear of recurrence.^{5,6} Given the large population and research funding, most studies in adults have been conducted among female breast cancer

survivors. Cancer survivors, however, represent a heterogeneous group with more than 100 distinct diseases, with a wide range of treatments, social and demographic characteristics, and other comorbid health conditions.⁷ For this reason, the Office of Cancer Survivorship has called for research on survivorship issues facing adults with understudied cancers.⁸

Melanoma is one such understudied cancer.⁹ The unique characteristics of melanoma -- its occurrence among males and females, the young age at diagnosis for some, and the range of treatment therapies -- argue for research that captures the specific issues faced by melanoma survivors. A better understanding of the long-term effects of a melanoma diagnosis is needed as clinicians and researchers develop appropriate follow-up care guidelines and create educational and other interventions as needed to improve the duration and quality of life of melanoma survivors.

1.2 Melanoma

Melanoma is a malignant tumor of melanocytes and mostly occurs in the skin. The lifetime risk of developing melanoma of the skin is approximately 2.1% percent. Of the seven most common cancers in the United States, melanoma is the only one for which incidence has been increasing and the “melanoma epidemic”¹⁰ has shown little signs of trend reversal.^{11,12} It is diagnosed primarily among non-Hispanic whites, however ethnic minorities with melanoma are known to have worse prognosis.¹³ The incidence of melanoma is higher among males than females, particularly those at older ages, though both sexes are well-represented. While the median age at diagnosis is 62, many young adults are diagnosed with the disease.¹⁴ Melanoma is the most common form of cancer

for young adults 25-29 and the second most common form of cancer for young adults 15-29 years old behind lymphoma.¹⁵

Melanoma is considered one of the most preventable types of cancer, with excessive ultraviolet radiation (UVR) exposure being one of the strongest factors.^{16,17} Additional risk factors include increased number of moles and/or freckles, fair skin, light hair, eye color, family history of melanoma, and immune suppression.¹⁸ Even when diagnosed at an early stage, melanoma can be aggressive, and resistant to treatment.¹⁹ Unfortunately melanoma also has high rates of recurrence, even if diagnosed at an early stage, with excess risk of recurrence remaining 20 years or more after the initial diagnosis.^{20,21}

The treatment strategies used in melanoma are diverse and treatment-related morbidity can be significant. Most individuals have surgery for their melanoma and a proportion of these have either sentinel lymph node biopsy or lymphadenectomy.²² Lymphedema, a late-effect of surgical management of melanoma, has not been well characterized in survivors and could vary from 2-19% in the upper limbs and 18-64% in the lower limbs.²³⁻³² Patients with stage III and selected stage IIB melanomas may be offered interferon α -2b adjuvant therapy, which is thought to delay recurrence though improvement in survival has not been consistently shown.^{33,34} This treatment is associated with significant toxicities resulting in (% of patients): severe fatigue (21-24%), severe cytopenias (10%), depression (40-72%), suicidal ideation (up to 10%), and grade 3-4 hepatotoxicity (27-29%). Frequent follow-up and blood tests are necessary while patients are receiving therapy, representing both financial costs and further alterations in

quality of life.³⁵⁻³⁷ For those with metastatic disease, therapy can include immunotherapy with agents such as interleukin-2 and ipilimumab, targeted therapy with *BRAF* inhibitors, or chemotherapy using dacarbazine, temozolomide or platinum and paclitaxel combinations.^{38,39} Toxicities include hypotension, fluid overload, pulmonary edema, renal insufficiency, nausea, vomiting, and hallucinations. Some treatment options can cause chronic toxicity such as acute auto-immune diarrhea, skin rashes, or deficiency in hormone secretions related to auto-immune destruction of hormonal glands (pituitary, adrenal, and thyroid). In addition, the long lasting side effects of therapy with platinum and paclitaxel regimens can include neuropathy, auto-toxicity, and renal insufficiency.

The young age at melanoma diagnosis for some and high risk of recurrence leads to an estimated 15-20 years of potential life-lost.⁴⁰⁻⁴² Melanoma ranks seventh in number of years lost among all cancers,⁴³ lower than childhood cancers but similar to Hodgkin's lymphoma and breast cancer. This raises questions regarding the effect of the diagnosis on quality of life, issues of parenting, employment, health insurance and access to health care, lifestyle, and continued surveillance.

1.3 Quality of Life

Quality of life (QOL) is a multi-dimensional concept that incorporates three overlapping domains of function: physical, psychological, and social, as they relate to health status.⁴⁴ Change in QOL is a recognized major health outcome of cancer diagnosis and treatment, which may impact a patient's prognosis, including survival.⁴⁵⁻⁴⁷ Individuals' overall life satisfaction, perceptions of their health status, and ability to take part in valued activities are components of QOL.⁴⁴ QOL can be significantly affected by

pain, fatigue and other symptoms of cancer and treatment side effects. It has been shown to differ by cancer diagnosis, stage of disease, and time from diagnosis.⁴⁸⁻⁵⁰

Melanoma survivors are a unique population to evaluate in terms of alteration of QOL related to their diagnosis or treatment, as they are younger than other cancer populations and have a significant risk for tumor recurrence or for a second primary. Despite this and the rising incidence of melanoma, few studies have explored this population. Data on QOL are available on those with advanced stage melanoma undergoing experimental treatments,⁵¹⁻⁶⁷ however little is known about specific survivorship issues faced by those with early stage disease or who have survived many years.⁶⁸ This is further complicated by the lack of control groups within studies, making it hard to conclude whether any differences in QOL are attributable to the melanoma diagnosis.

1.3.1 Physical Domains

Changes in the physical functioning of persons living with cancer affect their ability to perform physical activities and carry out social roles (e.g. employment, household chores). Issues can include fatigue, pain, and functional limitations leading to difficulties with returning to work and maintaining previous physical activity levels.² Physical performance has been shown to be lower in cancer survivors compared to healthy controls.⁶⁹ Among melanoma survivors in particular, treatment-specific physical symptoms include fatigue and nausea associated with adjuvant therapy,^{51,58,59} and altered sensation and pain at surgery site.⁷⁰ Importantly, a recent study found that physical role functioning is associated with time to recurrence and survival among patients with

melanoma receiving interferon treatment.⁷¹ It is unknown, however, what proportion of melanoma survivors experience these issues, compared to healthy controls, and if they remain long-term.

1.3.2 Psychological Domains

Because most cancers are life-threatening, disruptions in emotional health are expected. Research to date suggests anxiety is more prevalent than depression in long-term cancer survivors compared to controls, generally due to fear of cancer progression or recurrence.⁷²

As most melanoma survivors are treated with surgery only, particularly those with early stage disease, it has been postulated that QOL issues in this population are likely psychological in nature.⁶⁸ Studies among melanoma survivors have found that approximately 30% have clinically significant levels of distress,⁷³ which is similar to other cancers.⁶⁸ This is worst around time of diagnosis and is believed to decrease over time. Adjuvant therapy for melanoma, in particular interferon, is associated with increased depression and emotional issues.^{56,58,59,67} In addition to treatments received, known risk factors for emotional distress in melanoma survivors include being female, younger and less educated and those lacking social support.⁷³ As with physical concerns, psychological issues have been found to be associated with survival among those with both early and advanced stage melanoma.^{74,75} For this reason, it is important to understand whether melanoma survivors are at increased risk of poor emotional QOL compared to controls and what characteristics are associated with these outcomes.

1.3.3 Social Domains

Social support is associated with good psychological adjustment and better coping strategies among cancer survivors.^{73,76,77} The relationship between social support and cancer progression has been extensively explored among breast cancer survivors, though the data are less convincing for other cancers.⁷⁸ In addition to social support potentially affecting cancer outcomes, a cancer diagnosis can also affect social relationships. For example, a recent study found that young adult cancer survivors face higher risk of divorce.⁷⁹

Among patients with metastatic melanoma, low levels of social support were associated with distress and lower emotional QOL.⁸⁰ In contrast, another study did not find an association between melanoma-related distress and perceived social support.⁸¹ This may represent a dichotomy in experiences; some melanoma survivors report their diagnosis had a positive impact on their life because it strengthened family relationships⁸² whereas others have stated they feel socially isolated when others want to spend time in the sun.⁸³ Understanding social concerns among melanoma survivors is necessary, particularly as many are young at the time of diagnosis.

1.4 Risk Factors among Cancer Survivors

It is anticipated that physical, emotional, and social QOL concerns among melanoma survivors may differ by demographic and clinical characteristics. A key factor is sex. Sex is an independent prognostic factor for surviving melanoma, with females surviving longer than males.⁸⁴⁻⁸⁸ Females with melanoma, however, also appear to have higher levels of distress, anxiety, and emotional stress than males.^{81,89-93} Another study suggested females may experience more pain, itchiness, and numbness at their melanoma

surgical site than males.⁹¹ Finally, in a study among females with early stage melanoma, the majority reported poorer self-image and concern about recurrence.⁹⁴ Interestingly, a large study of melanoma survivors found males were more likely to believe cancer had affected their overall health than females.⁸² A potential complicating issue to the relationship between QOL and sex among melanoma survivors may be age. Studies exploring the relationship between age and distress have found conflicting results.^{82,95} It may be that the effect of age is not linear; younger survivors may be more likely to experience emotional issues, particularly females, and older adults may experience more physical issues, which may be similar by sex.

Cancer stage and treatments are also associated with QOL though this has not been consistently found in melanoma. One study found an association between melanoma stage and physical and emotional QOL.⁹¹ Two studies, however, found no association between disease stage and emotional QOL.^{81,96} Melanoma survivors receiving combination therapy report lower QOL compared to those receiving surgery alone.⁸² An interesting association between social support and treatment was observed in one study, with those with advanced stage undergoing adjuvant therapy reporting higher social support, in part due to the additional support received by health professionals.⁹⁵

A few other characteristics have been considered, including education, family history of melanoma, and number of co-morbidities.^{89-91,97} Exploring potential predictors of QOL in this population is important so those at risk for lower QOL can be identified and intervened upon.

1.5 Sun Protection

UVR exposure, from the sun or indoor tanning, is an established risk factor for melanoma^{98,99} and indoor tanning has been associated with the development of melanoma.¹⁰⁰ For melanomas that develop as a consequence of UVR exposure, the damage done to the skin by UVR exposure behavior prior to the first melanoma cannot be ameliorated and this damage may increase risk of a subsequent melanoma. However, it is thought that UVR exposure following a melanoma diagnosis can be modified to reduce risk of a new melanoma diagnosis.¹⁰¹

It has been suggested that cancer may be a “teachable moment” for health behavior change.¹⁰² Unfortunately, while some survivors initiate positive health behaviors, others do not.¹⁰³ In the case of melanoma, reduction of sun exposure is paramount. Individuals are advised to limit time in the sun during peak hours, seek shade, wear protecting clothing, use sunscreen, and avoid indoor tanning devices.¹⁴ Surprisingly little research has documented UVR exposure among melanoma survivors. Studies to date on sun exposure and protection behaviors among melanoma survivors have been mixed. A recent qualitative study found that melanoma survivors reported being more conscious of sun exposure and protection.⁸³ Another study found that 56.6% of melanoma survivors reported not sunbathing because it is harmful, compared to 16.6% of a control group.¹⁰⁴ A large online survey found that despite a melanoma diagnosis, 38% of melanoma survivors reported intentional tanning in the past year¹⁰⁵ and 27% reported at least one severe sunburn in past year.¹⁰⁶ Another population-based study found similar use of indoor tanning among melanoma survivors and non-cancer controls.¹⁰⁷ The timing of these surveys in relation to diagnosis may explain differences

in results, however. A small prospective study of melanoma survivors found that initially UVR exposure was lower among survivors the first year after diagnosis compared to a control group but then it converged over the three year study.^{108,109}

A few studies have found increases in sun-protection behaviors among melanoma patients following diagnosis.¹¹⁰⁻¹¹² Barriers to sun protection in the general population have been identified as “inconvenience, forgetting to use sun safety measures, desire to be tanned, and protective clothing being too hot to wear.”¹¹³ In comparison to non-cancer controls, two studies found that melanoma survivors use sunscreen and seek shade more frequently than non-cancer controls,^{106,107} whereas another study found sun protection behaviors were comparable but not greater than general population estimates.¹¹⁴

These studies suggest that if an improvement in sun behaviors among melanoma survivors is present, it is moderate. Further clarification of these behaviors in long-term melanoma survivors is needed, particularly in comparison with an appropriately matched control group. In addition, characteristics of those who do and do not improve sun protection are not well understood. A population-based study of melanoma survivors in Europe reported that females adjust their sun protection behaviors more than males;⁹¹ sex differences have been found in other studies.¹¹⁴⁻¹¹⁷ Bowen et al. found females were more likely to use sunscreen and males were more likely to wear protective clothing, particularly hats.¹¹⁶ Another study found that females reported fewer sunburns and were more likely to stay in shade or use sunscreen whereas males were less likely to indoor tan and more likely to wear protective clothing.¹¹⁷ Additional factors that may be important include age, skin type, and family history of melanoma, though these have not been

extensively studied. A better understanding of these factors is necessary to know where to direct intervention efforts.

1.6 Limitations of Existing Research

Research to date on cancer survivors has not focused on those diagnosed with melanoma. In particular, studies on long-term survivors of melanoma are lacking. QOL is now recognized as an important outcome for patients with advanced and metastatic melanoma undergoing adjuvant therapy, but few researchers have focused on these outcomes among those with early stage disease. Studies that have been reported included either small sample sizes or did not have a control group with measured confounders. Because of these limitations, reported study results have been mixed and generally inconclusive.

1.7 Assessment of QOL among Melanoma Survivors

Although numerous instruments exist for the measurement of psychosocial factors, overall QOL, and health behaviors in relation to cancer, they are considered too general and inadequate for addressing the wide range of concerns among those surviving melanoma.^{9,82,118,119} To date, a limited number of studies examining QOL issues have been carried out in long-term melanoma survivors. The majority of these studies relied on currently available generic and cancer-specific instruments to assess a narrow range of issues, primarily related to emotional distress, anxiety, depression and psychosocial adjustment, or overall QOL.^{45,54,58,65,82,92,114,118,120-129}

Few instruments have been developed specifically for melanoma survivors and those that have focused on the time just after diagnosis and treatment. Two instruments

exist to date: the Functional Assessment of Cancer Therapy – Melanoma (FACT-M)^{130,131} and the recently pilot tested Melanoma Module for the European Organization for Research and Treatment of Cancer (EORTC), which was designed for use in international clinical trials of melanoma treatment.¹³² The unique characteristics of melanoma underscore the need to develop a questionnaire that captures the specific issues faced by melanoma survivors as they move beyond the diagnosis and treatment period.

1.8 Dissertation Purpose

With incidence of melanoma increasing, the number of long-term melanoma survivors is increasing; therefore it is important to understand the long-term effects of the diagnosis on QOL and health behaviors. The purpose of the work outlined in this dissertation was to 1) document the breadth of long-term effects of a melanoma diagnosis and treatment on survivors via focus groups; 2) create a comprehensive questionnaire for assessing these effects; and 3) conduct a cross-sectional study of long-term melanoma survivors and population controls to assess and compare QOL and sun exposure and protection behaviors.

2 Part I: Qualitative Assessment of Melanoma Survivors and Questionnaire Creation

The overarching goal of this dissertation was to document the long-term effects of a melanoma diagnosis and treatment on survivors and compare their QOL and health behaviors with population controls. Since existing instruments for assessing QOL in this population focused primarily on immediate concerns following treatment, the first step in accomplishing this goal was to develop a more inclusive and comprehensive questionnaire. The next two chapters describe the work performed to create a questionnaire for long-term survivors, with appropriate items for population controls.

First, a series of focus groups were conducted to describe the breadth of experiences among melanoma survivors, focusing on the experience at diagnosis, ongoing physical, emotional and social concerns, and behavioral changes since diagnosis. (Chapter 3; Manuscript 1). Then a questionnaire was developed to address the concerns identified during the focus groups using currently available standardized instruments when possible and pilot tested in melanoma survivors (Chapter 4).

3 Part I: Paper 1 - A qualitative study of quality of life concerns following a melanoma diagnosis

3.1 Introduction

Melanoma, one of the most serious types of skin cancers, is unlike most common cancer types in that the incidence has been increasing over the past 30 years.^{11,12,133} With a 5-year survival rate of 91%, currently over one million melanoma survivors are living in the United States.¹ Even when diagnosed at an early stage, however, melanoma can be aggressive, resistant to treatment, and has the ability to metastasize even at the earliest stages.¹⁹ These factors, and the young age at diagnosis for some, lead to an estimated 15-20 years of potential life-lost,⁴⁰⁻⁴² ranking melanoma seventh in number of years lost among all cancers in the United States.⁴³ Melanoma also has high rates of recurrence, even if diagnosed at an early stage, with excess risk of recurrence remaining even 20 years after the initial diagnosis.^{20,21} A better understanding of the long-term and late effects of a melanoma diagnosis is needed as clinicians and researchers develop appropriate follow-up care guidelines and create educational and other interventions aimed to improve the lifespan and QOL of melanoma survivors.

QOL is a multidimensional concept that incorporates physical, psychological and social functioning and an individuals' overall life satisfaction, perceptions of their health status, and ability to take part in valued activities are important components. Although numerous instruments exist for the measurement of psychosocial factors and overall QOL in relation to cancer, they are considered inadequate for addressing the wide range of concerns among those surviving melanoma.^{9,82,118,119} To date, a limited number of

studies examining QOL issues have been carried out in long-term melanoma survivors.

The majority of these studies relied on currently available generic and cancer-specific instruments to assess a narrow range of issues, primarily related to emotional distress, anxiety, depression and psychosocial adjustment, or overall QOL.^{45,54,58,65,82,92,114,118,120-}

¹²⁹ Few instruments have been developed specifically for melanoma survivors and they focus on the time just after diagnosis and treatment: the Functional Assessment of Cancer Therapy – Melanoma (FACT-M)^{130,131} and the recently pilot tested Melanoma Module for the European Organization for Research and Treatment of Cancer (EORTC), which is designed for use in international clinical trials of melanoma treatment.¹³² The unique characteristics of melanoma -- its occurrence among males and females, their comparatively younger age, and range of treatment therapies used – underscore the need to develop a questionnaire that captures the specific issues faced by melanoma survivors as they move beyond the diagnosis and treatment period.

The objective of the research reported here was to conduct focus groups to identify a relevant and inclusive list of QOL issues among melanoma survivors to form the basis of a questionnaire. Instead of focusing solely on the period of time immediately surrounding melanoma diagnosis and treatment, as others have done, we were interested in studying the issues survivors face as they live beyond their treatment.

3.2 Methods

3.2.1 Study Participants and Recruitment

The study was approved by the University of Minnesota Institutional Review Board (1201M09423). A convenience sample of patients treated by dermatologists and

oncologists at the University of Minnesota were identified for participation in this study. English speaking individuals diagnosed with stage I-III cutaneous melanoma in Minnesota since 2008, ages 18-65 years old at diagnosis, were eligible for this study. The age limits were imposed to match the eligibility criteria of a previous study conducted by the Principal Investigator (PI, D. Lazovich).¹⁰⁰ Eligible individuals were sent an invitation letter, co-signed by their dermatologist, oncologist or surgeon, and the PI. Potential participants were then called to see if they were willing to participate in a focus group. For those who agreed, a reminder letter was sent including a consent form to review prior to arrival.

3.2.2 Focus Groups

Focus groups were conducted to identify survivorship issues faced by people diagnosed with stage I-III melanoma. Groups were conducted separately for those with early stage disease (I and II) and advanced stage disease (III) due to the differences in treatments received. Due to previous reports of differences in psychological adjustment after a diagnosis of melanoma between sexes,⁹² focus groups were also held separately for males and females when possible. Five groups were formed from 33 participants, consisting of two all-male early stage melanoma groups (n=6 and 7), two all-female early stage melanoma groups (n=8 and 7) and one mixed-sex advanced stage melanoma group (n=5).

The focus groups lasted approximately 90 minutes each and were held on the University of Minnesota Minneapolis campus. Participants provided written informed consent immediately prior to the start of the discussion. Each session was digitally

audio-recorded and participants received \$75 for their participation. All groups had the same moderator (DL) and co-moderator (RIV) and followed established methods for conduct of focus groups.¹³⁴

The question guide for the focus groups was developed iteratively. First, an extensive review was conducted of the literature that included published reports of QOL in melanoma survivors as well as existing QOL questionnaires. The data from these studies were used to generate a list of topics thought to be important among persons diagnosed with melanoma. These topics were reviewed by all investigators and then refined into broad questions to serve as the focus group moderator guide.¹³⁵ The final questions included are presented in Table 1 and related to experience at diagnosis, physical, emotional and social concerns since diagnosis, and behavioral changes since diagnosis.

At the end of each session, the moderator summarized key points discussed during the focus group and requested feedback from the group regarding the accuracy of the summary. After each session, the moderator and co-moderator discussed their observations and impressions of the content and process of the focus group session. All recordings from the focus groups were transcribed.

3.2.3 Analysis

We used standard procedures of qualitative thematic text analysis to analyze the focus group transcripts.¹³⁵ Two researchers (DL and RIV) independently read the transcripts and agreed to broad themes from the focus group discussions. Each researcher then conducted an analysis using descriptive coding techniques.¹³⁴ Results were

compared for consistency and thoroughness and overarching themes and sub-topics were agreed upon. A preliminary summary was mailed to all participants. Notes taken during the interviews were used to complement the conclusions. Exemplary quotes from participants are provided as appropriate and presented verbatim; therefore they were not corrected for grammar or word choice.

3.3 *Results*

We identified 105 eligible melanoma patients, of whom 72 (68.6%) indicated they were willing to participate; 33 ultimately participated (31.4%). Among those who expressed initial interest but did not participate, the most common reason given was scheduling conflicts. Those who participated were similar to those who did not participate in sex and age. Participants were evenly distributed by sex (54.5% female), and most had a history of Stage I disease (63.6%) with 18.2% each with a history of either Stage II or Stage III disease; the mean age was 49 ± 13 years. About one-third had family history of melanoma or a personal history of other skin cancers.

3.3.1 *Experience at diagnosis*

Following introductions, each focus group started with a discussion of what participants experienced at the time of the melanoma diagnosis. The large majority of participants reported feeling shock, fear and disbelief of the severity of the diagnosis.

“Fear, screaming. It’s a word [cancer] you don’t ever want to hear. That was my initial reaction.”

A few said they had noticed changes in their mole but that their concerns were assessed as normal by healthcare providers. They expressed anger when they finally

received the diagnosis of melanoma.

“I was angry [...] I had been questioning this spot for a year and had been told it was nothing and not to worry about it. So learning that it was melanoma, I was angry.”

Once diagnosed, most reported having surgery within a few days. Participants said the rapid pace of treatment was overwhelming as they tried to process the diagnosis, learn about melanoma, and undergo surgery. Many admitted they had little knowledge about melanoma before their diagnosis, which made the process more difficult. Those with early stage disease reported being thankful their disease was caught early, however those with stage II and III disease described difficulty making decisions regarding additional therapy.

“[My doctor] really just gave me all the options of why I should do it, and reasons why I may not want to do it. Really let me make that decision on my own and talk to my family about what I wanted to do. Whether I thought it would help, whether I should do it, whether I shouldn’t.”

As with many cancers, some described their melanoma diagnosis as a devastating and traumatic experience. In particular, those with younger children reported having concerns about their families and family members would process the information.

“I was sure that, at the time, this is it, I’m dying, this is it. I was absolutely petrified and absolutely scared to death.”

In contrast, while not the majority, a few reported their diagnosis was not particularly concerning, neither at the time of diagnosis nor in survivorship.

“I feel like I’m in the wrong group because mine was no big deal.”

“I would never say necessarily I had cancer, I had a mole with cancer.”

Finally, a few reported feeling guilty and angry at themselves about the time they spent in the sun early in their life as they attributed that to leading to their melanoma.

3.3.2 Physical Concerns

Next we asked about physical concerns, both at the time of diagnosis and in the survivorship period. Some participants reported lingering physical concerns, including pain, numbness, and lymphedema. A few noted some restrictions and limited motion during recovery that resolved with time and/or physical therapy. The few participants who received adjuvant therapy reported additional side effects, with fatigue described as the most troublesome and pervasive.

“My melanoma was on the side of my face. So they went in to the neck resection and they went so deep that I was in a lot of pain... I still have neck pain on that side of my neck.”

“I wear compression garments on usually a daily basis to keep all that fluid from moving everywhere.”

A few with stage I disease and small tumors reported minor surgeries and no physical changes of note.

“I didn’t have any problem. I walked out of the doctor’s office and went back to work. That’s it.”

Lastly, some reported requiring extra vitamin D supplementation and a few noted still struggling with low levels and the resulting fatigue that they attributed to sun

avoidance.

3.3.3 Emotional Concerns

The majority of participants reported longer-term concerns that were emotional in nature, with most experiencing some form of anxiety. A few reported general anxiety, whereas others were worried about follow-up checks and tests, their general health, and were fearful of other cancers and melanoma for themselves and their children. Some reported their anxiety improved with time, while for others the anxiety remained years after their diagnosis.

“You listen to every one of us, the anxiety is the one thing that really got us. It’s the anxiety, and the anxiety continues.”

“...you get really uptight just before that scan. I don’t even realize but my husband says, ‘you’re so bad the week before you scan’.”

“When I start feeling icky from other things, that’s one of the first things that pops into my head. I wonder if I have cancer.”

A number of participants said they were surprised by the size of their scar and were self-conscious about it and the changes to their self-image.

“It was just a teeny, tiny spot and they cut all the way down to the muscle and took all the tissue just for preventive.”

“When they ended up taking that piece out of my cheek, I remember looking in the mirror, and I still do it, but I have learned to control the hysteria. I look in the mirror and I don’t see my normal face.”

“I get asked about my scar all the time. Drives me nuts, because it’s

something I hate.”

Many reported relying on their family for emotional support, whereas a few participants reported their faith and spirituality was important for maintaining their emotional health. Some participants, however, reported difficulty discussing melanoma with their family.

“I think if I didn’t have the support that I had at the time, it would have been a completely different story.”

“I wish I could talk more about it because, I tell you, it’s almost a taboo subject in my family. They just don’t want to hear about it. It’s fear or something.”

Several participants also noted feeling lonely and isolated despite family support. Interestingly, this issue came up not during the discussion of emotional health, but at the end of the focus groups when we asked subjects their motivation for participating in our study. We consistently heard how appreciative they were of the opportunity to participate in the discussion group as an opportunity to meet with others diagnosed with melanoma.

“...it was kind of nice to be able to leave here today and not feel alone.

Because that was my biggest thing, I constantly felt alone. Like I was the only person who had it...”

3.3.4 Social Concerns

When asked about any social changes, participants noted a number of social concerns, including altering social activities to avoid sun exposure and wanting to

educate others about melanoma. Most expressed a desire to not let their diagnosis affect their interactions; however some were careful to limit activities in the sun.

“...once or twice in the summer we go camping now instead of almost every weekend.”

Some reported feeling the need to educate others about melanoma and prevention strategies. In particular, many reported being frustrated by the lack of appreciation by others of the seriousness of melanoma.

“I was amazed by the number of people who hear melanoma, and they’re like, oh that’s skin cancer, not a big deal.”

“My big thing is getting other people to understand how serious this is.”

A few reported not having insurance or having a high deductible plan and therefore faced difficulties with financial uncertainty and receiving optimal care. Quite a few also stated trouble obtaining life insurance after the diagnosis.

“The reason I never got the mole taken off [earlier] was because I didn’t have insurance initially.”

“I had a high deductible insurance, so I kind of choose what my aftercare is, because budget-wise I don’t necessarily do everything the doctor is asking me, every test.”

3.3.5 Behavioral Changes

When asked about any changes in health behaviors since diagnosis, many participants reported behavior changes. Some were limiting their time in the sun and increasing the use of protective clothing and sunscreen when in the sun, particularly those

with higher stage disease.

“I don’t see the sun.”

“I have a lot of those long-sleeve shirts and it will be 86 degrees outside and I’ll put on this long-sleeve shirt and I’m just sweating. But I wear them.”

Others, however, reported little to no change in their sun protection methods.

“Probably not the right thing to do, but I very seldom use sunscreen.”

In addition, some reported adopting a healthier lifestyle, including losing weight, exercising more, and reducing work load. A few others also reported placing higher value on family and that their family became closer.

While most followed their physician’s recommendations regarding surveillance, a few reported ignoring or postponing check-ups, particularly after the first year or two.

3.3.6 Identity as Cancer Survivor

As our goal was not only to summarize the experience of those diagnosed with melanoma but also to understand how future researchers might approach them, we asked participants whether they considered themselves to be cancer survivors. The responses were approximately evenly split between yes and no, but the explanations were diverse. All with Stage III disease identified as cancer survivors, indicating both the literal stance that melanoma is cancer and also noting that it is a very serious cancer.

“I have a close friend that has breast cancer... she was doing regular chemo and so I know all of that is just as grueling. But I don’t think people realize sometimes that the stuff we do is just as grueling or it’s the same thing. Cancer is cancer.”

Some with early stage disease, when asked about being a cancer survivor, said yes as well, though a few participants noted they felt there was a spectrum of cancer survivorship:

“Knowing what I know now about melanoma, yeah, I think I am a cancer survivor because it would have killed me if I would have ignored it and let it go.”

“I do, but I don’t consider myself like a hard core cancer survivor.

Technically I had it, I survived it.”

“If you took a level of cancer survivor I would consider myself a one compared to a ten.”

Participants who responded in the negative came from two different philosophies. Some did not consider melanoma serious enough or felt it was inappropriate because they did not have chemotherapy or radiation.

“I don’t want to downplay melanoma, but when you say cancer survivor... that’s... I don’t want to upset anybody, but I really don’t consider melanoma like pancreatic cancer or breast cancer. I’m kind of up in the air on that one.”

“I feel like I didn’t pay the full due with the chemo and the radiation and everything.”

A few others, however, did not like the term because they felt they could develop another cancer.

“I’ve had cancer twice. I’ve gone through it twice, I’ve survived it twice. I

don't consider myself a cancer survivor. I won't consider myself a cancer survivor until somebody looks me in the face and says, you know what honey, you're never going to get it again."

"I would say no, because I look at it more like I've won a battle, but the war is still going on."

3.4 Discussion

The objective of the study was to document the experiences of persons diagnosed with melanoma further from their diagnosis using focus groups. The experiences shared by participants in this study highlight a number of QOL issues facing melanoma survivors. QOL among melanoma survivors has been an active area of research over the past few years and our study compliments the results of others, confirming many of the same themes.

As previously reported, most participants reported being shocked and overwhelmed at the time of diagnosis and having significant information needs.¹³⁶⁻¹³⁸ Our data also support those of others who found melanoma survivors may experience treatment-specific symptoms such as fatigue and nausea, associated with adjuvant therapy,^{51,58,59} and lingering altered sensation and pain at the surgery site.⁷⁰ In addition, lymphedema was reported by a number of participants and resulted in notable complications, as reported by others with melanoma.¹³⁶ As important, some participants reported no physical concerns.

A systematic review found that most issues facing melanoma survivors are psychological in nature.⁷³ As noted by others, anxiety was the main concern of

participants in this study, though it manifested in numerous ways – general anxiety, fear of recurrence or of a new cancer, and fear of family members getting cancer.¹³⁹ For most, the anxiety was worst around time of diagnosis and decreased over time. Similar to other reports, participants also reported concerns about their surgical scars, including feelings of disfigurement and discomfort with comments about the appearance of their scar by others.^{136,137,140} We heard these concerns most notably among those with head or neck tumors and those with scars that were harder to disguise with clothing. While the terminology might have been different, we observed no obvious differences in any of these emotional concerns reported by age or sex.

As previously reported, for some participants their melanoma diagnosis had a positive impact on their life because it strengthened family relationships⁸² whereas others felt socially isolated when they felt they could not join others in outdoor activities involving sun exposure.⁸³ We were, however, surprised by the level of isolation and loneliness reported despite most participants stating that they felt generally supported by their families. This high level of isolation was also recently reported by Oliveria et al. (2013).⁸³ Upon probing, it appeared to be caused by the lack of public awareness about the seriousness of melanoma. Compared to breast cancer survivors, for example, who have many opportunities to network and meet other survivors, a need exists to increase both awareness of melanoma and chances for melanoma survivors to interact and support each other.

It has been suggested that cancer may be a “teachable moment” for health behavior change.¹⁰² Unfortunately, while some survivors initiate positive health behaviors, others

do not.¹⁰³ Among those who have already experienced melanoma, regardless of age, reducing sun exposure can decrease their risk of a new or recurrent melanoma diagnosis.¹⁰¹ Individuals are advised to limit time in the sun during peak hours, seek shade, wear protective clothing, use sunscreen, and avoid indoor tanning devices.¹⁴ Studies to date on sun exposure and protection behaviors among melanoma survivors have been mixed; some have reported most survivors being conscious of sun exposure and protection,^{83,106,107,110-112} whereas others report risky sun behaviors despite their diagnosis.^{105,106,114} The participants in this study suggest that both are true – while many alter their behaviors to avoid sun exposure, some report not changing their behavior.

Finally, participants were divided on whether they considered themselves a “cancer survivor”. Similar responses have been reported in other cancers, including breast, prostate, colorectal and hematologic cancers.¹⁴¹⁻¹⁴⁶ While most studies found the majority of survivors identify as being a cancer survivor, a significant proportion do not. Similar to our results, previous studies in other cancers have reported that those who do not endorse the term stated concerns about the cancer not being severe enough or the future being uncertain, particularly among those with a high risk of recurrence.^{142,143,147} Due to the complexity of this issue, we encourage cautious use of the term “cancer survivor” when working directly with those with melanoma and instead recommend “person diagnosed with melanoma” until further research on the preferences of this population can be conducted.

The main strength of this study is the use of qualitative methods. Collecting data using focus groups allowed for a detailed and in-depth assessment of melanoma

survivorship issues. These methods particularly permitted for capture of experiential personal information. We also focused on survivors of early stage disease, in contrast with most previous research. This study is not without limitations, however. The participants were one to four years from diagnosis and were from a single institution, an academic medical center. In addition, we had few participants who had undergone adjuvant therapy. Therefore, the results here may not be generalizable to all melanoma survivors. In addition, qualitative research can also be difficult to summarize in an objective way and despite efforts otherwise, our presence during data collection (i.e. conduct of focus groups) may affect the subjects' responses.

As early detection and treatments improve, cancer survivors will continue to be a growing portion of the population and an understanding of their needs and concerns is necessary to improve their QOL. Until now, an adequate questionnaire for assessing the full range of QOL experiences in melanoma survivors beyond the treatment period did not exist. Results from our focus group study suggested that no single survey covers all relevant issues, but a compilation of selected items from existing surveys can be constructed to cover most issues (Table 2).

To that end we have used these focus group data and the instruments listed in Table 2 to create a comprehensive questionnaire, which we are now administering to individuals, both those with and without melanoma. For comparison with other studies and populations, including those who are cancer-free, we included generic QOL measures such as the SF-36.¹⁴⁸ However, cancer- and melanoma-specific measures are also needed. Our selection process balanced the need to be inclusive of all QOL topics

identified by our focus group participants, while minimizing the number of questions. For particular topics of interest, such as lymphedema, we supplemented existing questionnaires with new questions. Our data also point to the importance of healthcare costs and need for insurance, topics that were excluded from the EORTC melanoma module as the questionnaire was developed primarily in Europe where healthcare costs are not as relevant.¹³² Thus, we have also included questions on these issues.

The high risk of recurrence and progression has led to researchers recently stating that melanoma can be considered a chronic disease.¹³² With melanoma incidence on the rise and the unique nature of the disease both in terms of its potential early age of onset and severity, understanding the experiences of melanoma survivors is necessary from a public health perspective to promote optimal health and QOL in this growing population. The results of the focus groups reported here have informed a large scale survey study currently underway. The ultimate goal is to take the knowledge gained to create interventions designed to improve the health and QOL of melanoma survivors.

Table 1. Focus group question guide.

- | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none">• Think back to the time of your melanoma diagnosis.<ul style="list-style-type: none">○ What ran through your mind?○ Was there anything particularly difficult or surprising about the surgery/treatment?• What changes have you noticed since diagnosis?<ul style="list-style-type: none">○ Physical○ Emotional○ Social• Have you changed any behaviors since your diagnosis?• Was there a silver lining to this experience for you?• Do you consider yourself a cancer survivor? |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Table 2. Recommended topics for comprehensive assessment of melanoma survivors.

<i>Topic</i>	<i>Items from Existing Questionnaires</i>
Diagnosis Experience	
Cancer diagnosis	• American Cancer Society SCS-II ¹⁴⁹
Healthcare system experience	• National Survey of Households Affected by Cancer ¹⁵⁰ • Patient Satisfaction with Cancer Care ¹⁵¹
Physical Concerns	
General concerns	• SF-36 ¹⁵²
Effects of surgery/treatment	• FACT-M ¹³⁰ • Impact of Cancer ¹⁵³
Emotional and Social Concerns	
General concerns	• SF-36 ¹⁵²
Clinical anxiety and depression	• Hospital Anxiety and Depression Scale ¹⁵⁴
Self-image	• Skin Cancer Index ¹⁵⁵
Emotional effects of melanoma	• Quality of Life – Cancer Survivor ¹⁵⁶ • Impact of Cancer ¹⁵³
Work and insurance issues	• National Health Interview Survey ¹⁵⁷ • National Survey of Households Affected by Cancer ¹⁵⁰
Health Behaviors	
Sun exposure habits	• Sun Exposure and Protection Measures ¹⁵⁸ • Measures from Skin Health Study ^{100,159}
Other lifestyle behaviors	• American Cancer Society SCS-II ¹⁴⁹ • Behavioral Risk Factor Surveillance System Survey ¹⁶⁰ • Godin Leisure Time Exercise Questionnaire ¹⁶¹

4 Part I: Development a questionnaire to measure QOL in melanoma survivors

Following completion and analysis of the focus groups, the next step was to design and test a questionnaire to address the specific QOL issues faced by survivors of melanoma. Though briefly described in Chapter 3, more details are provided here, in addition to describing the pilot testing. The study team completed the development of the questionnaire in two phases: 1) selection of questionnaire items and scales; and 2) pilot study assessment of questionnaire feasibility and reliability in a convenience sample of melanoma survivors.

4.1 Phase I: Questionnaire Development

The data from the focus groups were reviewed to create a comprehensive questionnaire for assessing the QOL of melanoma survivors. Generic QOL measures were considered and used appropriately for planned comparisons with population controls and cancer- and melanoma-specific measures were considered to encompass all remaining issues. When needed, new items were created to address specific concerns not otherwise captured. The following three criteria were considered when developing the questionnaire, in this order:

1. Include all issues discussed during the focus groups and/or previously published in melanoma or other cancer survivors.
2. Use validated, previously developed questionnaires/questions when possible.
3. Reduce participant burden by choosing options with fewer questions.

Both my adviser (DeAnn Lazovich) and I reviewed the focus group topic results and available questionnaires independently to create lists of recommended questions. A

table of specific questionnaires considered is provided in Appendix A. These lists were compared and edited numerous times until consensus was met. The final topics and question sources included for pilot testing are listed in Table 3, including whether each would be asked of melanoma survivors and/or population controls. A few new items were added; specific questions and citations for each question are provided in Appendix B.

This compilation included numerous well-studied measures along with a few new questions as needed, as described below.

4.2 Questionnaire Items for Both Melanoma Survivors and Controls

4.2.1 Medical Outcomes Study Short Form 36 (SF-36) – Version 2

The SF-36 version 2 includes 36 items measuring QOL, including the following subscales: Physical functional, Role limitations due to physical health, Role limitations due to emotional problems, Energy/fatigue, Emotional well-being, Social functioning, Pain, and General health.¹⁵² While it does not include cancer-specific items, the SF-36 has been employed in numerous studies of participants with cancer, including melanoma patients (see review by Cormier et al., 2012¹⁶²). This questionnaire was included because it is commonly used in studies of both healthy and cancer survivor populations. The psychometric properties of SF-36 have not been formally tested in melanoma survivors, though they have in other cancer survivors and were found to be adequate.^{163,164} One potential concern is that the SF-36 is not cancer specific; therefore, it may not be sensitive enough to detect changes relevant to cancer.

4.2.2 Hospital Anxiety and Depression Scale (HADS):

The Hospital Anxiety and Depression Scale (HADS) instrument includes 14 items designed to screen for potentially clinically relevant anxiety and depression.¹⁵⁴ HADS is not cancer specific but is a short questionnaire that has been used in hundreds of health-related studies. It has high internal consistency and test-retest reliability in the general population and has been used in numerous previous studies of cancer survivors including those with melanoma.^{65,162,165-168}

4.2.3 Sun Exposure and Protection:

Measures of sun exposure and protection behaviors include 13 self-report items related to sun exposure and protection practices that were developed by leading skin cancer prevention researchers.¹⁶⁹ This short questionnaire is applicable to both melanoma survivors and the general population. Data on the reliability and validity among melanoma patients have not been published. Questions related to skin examination were slightly modified to ask about the past 12 months and two questions related to indoor tanning were added.

4.2.4 Other Health Behaviors:

The Godin Leisure-Time Exercise Questionnaire¹⁶¹ measures physical activity and has been previously validated and used in many studies of cancer survivors and healthy populations.¹⁷⁰ Measures of the number of fruit/vegetable servings, smoking history, alcohol consumption, and multi-vitamin and vitamin D use were adapted from the American Cancer Society Study of Cancer Survivors II (ACS-SCS-II) survey,¹⁷¹ Skin Health Study,¹⁰⁰ Iowa Women's Health Study,¹⁷² and the Behavioral Risk Factor Surveillance Survey (BRFSS) questionnaires.¹⁶⁰

4.2.5 Co-morbidities:

Assessment of comorbidities included presence of heart problems, hypertension, chronic back pain, arthritis, stroke, severe memory or concentration problems, lung diseases, stomach and/or intestinal problems, diabetes, depression, anxiety, neuropathy, and cancer diagnoses in both melanoma survivors and population controls using questions from the ACS-SCS-II survey.¹⁷¹

4.2.6 Work and Health Insurance:

Measures of current employment status, days missed due to illness in the past year and health and life insurance coverage in both melanoma survivors and population controls were derived from the ACS-SCS-II¹⁷⁰ and National Health Interview¹⁷³ surveys.

4.3 Questionnaire Items for Melanoma Survivors Only

4.3.1 Treatment for Melanoma and Physical Symptoms

Details collected relating to melanoma diagnosis and treatment included site of the melanoma, stage, treatments received, and whether melanoma recurred using questions from the ACS-SCS-II survey.¹⁷⁰ Measures of lymphedema (swelling) and treatment for lymphedema included items from the FACT-M¹³⁰ and new questions written with assistance from a dermatologist. The entire FACT-M subscale was not included because some items are relevant only near time of diagnosis or during active treatment. Additional items regarding numbness at the surgical site, range of motion, and other physical symptoms following treatment included questions from the FACT-M,¹³⁰

Impact of Cancer,¹⁵³ and the Skin Cancer Index.¹⁷⁴ All three measures have been used in studies of melanoma survivors and shown to be valid and reliable.^{162,175}

4.3.2 Experience with Health Care System

Items from the National Survey of Households Affected by Cancer¹⁷⁶ questionnaire were included to assess the experience of melanoma survivors with their health care professionals and treatment decision-making.

4.3.3 Impact of Melanoma Diagnosis on Work and Health Insurance:

Additional detailed measures on work and health insurance following diagnosis included items from the Work Concerns During and After Cancer Treatment questionnaire.¹⁷⁷ The Work Concerns During and After Cancer Treatment questionnaire has been tested in a population of females with gynecologic cancer near the time of diagnosis but has not been previously tested in those with melanoma.

4.3.4 Well-Being Associated with Melanoma Diagnosis

Items related to the impact of a melanoma diagnosis on emotional well-being, relationships and social interactions, and life outlook using measures from the Quality of Life – Cancer Survivors¹⁵⁶ survey (psychological and social concerns subscales) and the Impact of Cancer¹⁵³ survey (positive outlook and negative outlook subscales) were included. The Quality of Life – Cancer Survivors instrument was developed to measure specific concerns in long-term cancer survivors. In a group of survivors of many cancers, the measure had high internal consistency and test-retest reliability. Researchers also examined the validity (content, predictive, concurrent, construct, and discriminant) and

found all to be satisfactory. The Impact of Cancer has been shown to have moderately high internal consistency among all ten domains.¹⁵³

4.4 Phase II: Assessment of questionnaire feasibility and reliability

4.4.1 Survey Administration

The preliminary questionnaire, as described above, was programmed as an online survey in Research Electronic Data Capture (REDCap).¹⁷⁸ The survey is accessible anywhere with an internet connection, though it needs to be completed on a computer rather than phone or tablet. REDCap allows users to exit and return to the survey at any time without losing data. As the participant completes the questionnaire, the data are entered directly into the REDCap database, which uses a MySQL database via a secure web interface with data checks to ensure data quality. REDCap includes features to support HIPAA compliance with a full audit trail, user-based privileges, and integration with the institutional LDAP server.

4.4.2 Pre-Pilot test of Survey

Five participants from the focus group study agreed to complete and assess the first version of the online survey. They were paid \$50 as compensation for their time. Each completed a telephone or in-person interview about their experience with the questionnaire and detailed any specific technical difficulties they faced. The two most frequent issues included difficulty with entering the website URL and a glitch with one of the built-in logic functions. This information was used to modify and refine the questionnaire.

4.4.3 Pilot Test of Survey

After refining the questionnaire, a pilot test was conducted among a separate group of melanoma survivors, recruited in the same manner as the focus groups. The original plan was to obtain data on 35 participants to assess reliability using a test-retest method six weeks apart. Fewer potential participants were identified than expected and therefore a total of 41 eligible participants were mailed a study packet. The study packet included a letter describing the study, information for accessing the online questionnaire, and \$20. Each person who returned the questionnaire was asked to fill out the questionnaire a second time, six weeks later, receiving an additional \$20. Participants were reminded to return the questionnaire via mail and phoned two times if incomplete.

4.4.4 Analysis

Data were examined for coding errors, missing data or inconsistencies to identify potential problems with survey administration. An analysis of test-retest reliability was conducted on the primary scales/items for comparisons between melanoma survivors and population controls (SF-36, HADS, and sun exposure and protection behaviors). The interclass correlation coefficient (ICC) was used to assess questionnaire test-retest reliability for items with a continuous distribution. For categorical data, agreement between the two measurements was calculated using Kappa coefficients. For ordinal data, the weighted Kappa was calculated by giving different weights to disagreements according to the magnitude of the discrepancy. Landis and Koch¹⁷⁹ provide benchmarks for test-retest reliability statistics: 0.0-0.2=poor, 0.2-0.4=fair, 0.4-0.6=moderate, 0.6-0.8=substantial, and 0.8-1.0=nearly perfect.

4.4.5 Study Findings

The final recruitment was 27 (65.9%) melanoma survivors for the first administration; 21 (77.8%) completed both administrations. The median time between questionnaire administrations was 6.0 weeks (range 4.5-9.1 weeks). The test-retest reliability ICCs for the SF-36 and HADS subscales were mostly categorized as substantial with a few in the nearly perfect category and a few in the moderate category (Table 4).

The sun exposure and protection behavior measures had two items with fair agreement, some with moderate and some with substantial agreement. (Table 5).

The test-retest reliabilities reported here are similar to previously reported values for the HADS subscales,¹⁸⁰⁻¹⁸² though a little low for a few of the SF-36 subscales (previously found to be greater than 0.70).¹⁸³ Upon closer review, version 1 of the SF-36 was programmed into the online questionnaire in error instead of the more recent version 2. While the questions are the same, the number of response categories were updated in version 2 for a number of questions to enhance reliability.¹⁵² In addition, the reliability of the SF-36 decreases as time between administrations increases, with the six week interval considered to be on the longer end.¹⁵²

Some of the sun exposure and protection measures had lower reliability than anticipated. One possible reason for this is that participants may not have fully read the directions for this section: “For the following questions, think about what you do when you are outside during the summer on a warm sunny day.” Given that the first administration was conducted in August and the second in September/October, the differences in answers may reflect the changes in seasons. Therefore, the questions were

changed to include the instruction as part of each question; for example, “How often do you wear sunscreen” was changed to “When you are outside during the summer on a warm sunny day, how often do you wear sunscreen?” This is expected to correct the problem, though future summaries of these data by month of survey completion may need to be explored and time/season taken into account in analyses if survey administration covers a long period of time.

4.5 Final Questionnaire

Following completion of the pilot study, one question was added for both melanoma survivors and controls asking whether they have life insurance. One question was also added to the assessment of co-morbidities for controls to ascertain those who had a melanoma diagnosis following initial participation in the Skin Health Study. The SF-36 version 1 was replaced with version 2 as originally intended. Additional instructions were added to clarify the sun protection and exposure questions. No other changes were made.

Finally, paper versions of each questionnaire, in the form of booklets, were created as an alternative to the online questionnaire. The final online (Appendices C and D) and paper (Appendices E and F) questionnaires for melanoma survivors and controls are provided.

Table 3. Final Survey Topics and Measures

<i>Topic</i>	<i>Melanoma Survivors</i>	<i>Controls</i>	<i>Description of Measures/Scales</i>
Health Behaviors			
Physical Activity ¹⁶¹	X	X	Measure of strenuous, moderate and mild activity in past week.
Diet and Supplement Use ^{100,171,172}	X	X	Number of fruit/vegetable servings, multi-vitamin and vitamin D use, weight and height
UVR Exposure/Sun Habits ^{158,159}	X	X	Number of hours outside in summer, sunburns, use of sun protections methods, amount of time spent in sun to get tan, indoor tanning in past year
Alcohol Use ¹⁸⁴	X	X	Number of times drinking alcohol per week, drinks
Smoking ¹⁷¹	X	X	Current smoking and other tobacco use
General Well-Being			
Quality of Life - SF-36 ¹⁴⁸	X	X	General Health Quality of Life survey
Emotional Well-Being - HADS ¹⁵⁴	X	X	Measure of clinical depression and anxiety
Physical Health			
Co-morbidities ¹⁷¹ and Family History of Melanoma ¹⁰⁰	X	X	Assessment of co-morbidities and family history of melanoma
Cancer Experience			
Treatment Information ^{130,171,174}	X		Treatment received, pain and numbness at surgical site, appearance of scars, recurrence, swelling (lymphedema)
Healthcare system experience ¹⁷⁶	X		Rate health professionals, frustrations with care, and treatment decisions
Work and Insurance			
Work and health insurance status ^{171,173,185}	X	X	Current employment status, days missed due to illness in past year, and insurance coverage
Work status and benefits following diagnosis ^{171,176,185}	X		Questions related to work after diagnosis, changes in work effort or continued work, healthcare and life insurance, household income; modified for controls
Well-Being Associated with Melanoma Diagnosis			
Emotional effects of melanoma ¹⁵⁶	X		Emotional well-being after melanoma diagnosis
Social Concerns ¹⁵⁶	X		Impact of diagnosis on relationships and social interactions
Silver Lining ¹⁵³	X		Life outlook after melanoma diagnosis

Table 4. ICC test-retest reliabilities for the SF-36 and HADS (N=21).

Scale	ICC
SF-36	
Physical functioning	0.41
Role – Physical	0.86
Role – Emotional	0.47
Energy	0.69
Emotional well-being	0.80
Social functioning	0.70
Pain	0.70
General Health	0.87
HADS	
Depression	0.63
Anxiety	0.89

Table 5. Test-retest reliabilities for sun exposure and protection items.

Sun Exposure and Protection Items	Kappa Coefficient
Weekday hours of exposure	0.48
Weekend hours of exposure	0.42
Burns in past year	0.73
Sunscreen use	0.78
Shirt	0.37
Hat use	0.73
Shade	0.47
Avoiding exposure to the skin	0.32
Indoor tanning	1.00

5 Part II: Cross-sectional study of long-term melanoma survivors and population controls

After the final questionnaire was developed, as described in Chapter 4, a cross-sectional study was initiated to evaluate the impact of melanoma on long-term survivorship, focusing on QOL and sun exposure and protection behaviors. Studies of long-term melanoma survivors are lacking, and the survivorship research to date has been limited by the inability to compare to a population control group. The primary data collection conducted in this dissertation overcomes the limitations of these previous studies.

The goals of this study were to compare QOL between melanoma survivors and population controls (Manuscript 2) and measures of UVR exposure and protection behaviors between melanoma survivors and population controls (Manuscript 3).

6 Part II: Detailed Methods for Primary Data Collection

6.1 Study Design and Population

A cross-sectional follow-up study of participants from the Skin Health Study, a previously completed case-control study described below, was conducted July-October 2015. Both melanoma survivors (cases) and controls were asked to complete the questionnaire developed in Part I of this dissertation. Approval for this study was granted by the University of Minnesota Institutional Review Board and the Minnesota Cancer Surveillance System.

The Skin Health Study served as the source of melanoma survivors and population controls for data collection for the remaining chapters. The Skin Health Study was a population-based case-control study conducted 2004-2009 in Minnesota by DeAnn Lazovich of the University of Minnesota with the primary goal of assessing the relationship between indoor tanning and risk of melanoma. This study was not only a resource for recruitment but provided a wealth of data collected at the time of diagnosis for both melanoma cases and age- and sex-matched controls.

Cases in the Skin Health Study were ascertained by the Minnesota Cancer Surveillance System, a population-based, statewide cancer registry. Individuals with invasive cutaneous melanoma diagnosed between July 2004 and December 2007, between the ages of 25 and 59, with a state driver's license or state identification card, were eligible to participate. These age cutoffs were chosen to correspond with indoor tanning use since that was the exposure of interest in the original study. In accordance with state laws, the cancer registry first obtained physician permission for research staff

to contact his or her patient before releasing case information to research staff; consent was assumed after allowing sufficient time for physician response. Controls were randomly selected from the Minnesota state driver's license list (which included persons with state identification cards) and frequency-matched to cases in a 1:1 ratio on age (in 5-year age groups) and sex. Eligible cases and controls were required to be English-speaking and to have a telephone number.

Data collection began in December 2004 and was completed in March 2009. Eligibility was determined for 72.5% of cases and 56.3% of controls. Among cases and controls for which eligibility could be confirmed, 1167 cases (84.6%) and 1101 controls (69.2%) completed data collection.

Data were ascertained using both a self-administered questionnaire and detailed computer-assisted telephone interview. Skin, hair and eye color, presence and pattern of freckles and moles, detailed indoor tanning and residential history, and supplement/medication intake were collected via the self-administered questionnaire.

6.2 Identification of Eligible Skin Health Study Participants for the Follow-up Study

All Skin Health Study participants who were alive at the time of the survey administration (Summer 2015) were identified. Deaths among cases and controls were identified using the Minnesota Death Index (data updated through April 2015) and additionally by the Minnesota Cancer Surveillance System using the National Death Index (data updated through July 2013).

The Minnesota Cancer Surveillance System required updated permission from the physician of record in the registry before re-contacting each person with melanoma

(case). They required two contact attempts. The 1167 cases were seen by a total of 619 different physicians. As only the original contact information for these physicians was available, updated clinic contact information was obtained by purchasing the mailing list from the Minnesota Medical Association. Each clinic was then called to confirm the physician's status and obtain the fax number. A form for each case seen by each physician was then faxed to the clinic, requesting permission or refusal to contact the case and signature. Active consent was sought initially by requesting that the physician indicate their consent by signing the document, giving his or her permission to contact the patient. If a signed fax was not returned within two weeks, a second fax was sent. Passive consent was assumed if the second fax was not returned within one week of sending. If the physician could not be located, retired, passed away, or was no longer treating the case and had no further information, participants were deemed eligible to be re-contacted.

The final eligibility status of all Skin Health Study participants is presented in Table 6 and physician contact materials are provided in Appendix G. Overall, 73 (6.3%) melanoma survivors and 9 (0.8%) controls were found to be deceased at this stage and physician permission to contact was obtained for 1075 cases (92.1%). A small number of the Skin Health Study controls (7; 0.6%) had previously requested no further contact for future research and were therefore ineligible for this follow-up study.

6.3 Subject Recruitment

Name, date of birth, address and telephone numbers from time of last contact were updated by an independent contractor using national internet databases prior to

conducting the study. For those for whom mail was returned and a forwarding address was not provided by the post office, additional methods to obtain a current address were used. This included reviewing a list of participants with updated addresses who moved in the last four years provided by the University of Minnesota mailing services, and an online search using WhitePages.com.

Recruitment methods outlined by Dillman were used to maximize response, including use of adaptive design.¹⁸⁶ A test batch of 90 each of melanoma survivors and population controls was mailed to assess the process. The initial plan included three mailings.

1. *Initial Letter*: An invitation letter explaining the study goals with the link to the online survey was sent to eligible Skin Health Study participants. Letters were tailored to melanoma survivors and controls separately. All mailings also included a consent form for their records and an online survey tip sheet. A study telephone number and email address was provided for participants who had questions or technical concerns.
2. *Thank You Card*: One week after the study materials were mailed, a full-color thank you card with a friendly reminder to complete the online survey was mailed to all participants, regardless of whether they completed the survey. Cards had a hand written salutation and signature.
3. *Reminder*: Three weeks after the initial invitation letter, the study materials were sent again to non-responders.

Due to low initial response rates following the thank you card, a decision was made to add a small incentive to the first mailing (\$4 in the form of two \$2 bills), re-write the letters to have a friendlier tone, and provide the paper survey to all participants with the reminder mailing. The paper survey was designed as a booklet with a full-color cover to ensure a professional look and return envelopes were hand stamped to encourage participation. In addition, a final reminder mailing was added. All changes were implemented prior to the reminder letter for the first batch. These individuals received their incentive with the reminder letter instead of the first mailing.

The final process of contacting and recruiting potential participants included:

1. *Initial Letter + incentive*: An invitation letter and materials were sent, as described above, with the addition of an incentive (two \$2 bills). The final materials are provided in Appendix H.
2. *Thank You Card*: A thank you card was mailed one week following the initial letter as described above. The card is provided in Appendix I.
3. *Reminder + paper survey*: Three weeks after the initial invitation letter, a reminder letter, copy of the paper survey and a postage-paid (stamped) returned envelope were sent to non-responders. A separate reminder was sent to those who started the online survey but had not completed it. The final letters are provided in Appendix J.
4. *Final Reminder*: Two weeks after the reminder letter and paper survey were sent, a final letter was mailed to all remaining non-responders (Appendix K).

The mailings were conducted initially in three batches: batch 1) 90 melanoma survivors and 90 controls (test group); batch 2) 510 melanoma survivors and 510 controls; and batch 3) 475 melanoma survivors and 485 controls. Due to a large amount of returned mail for participants for whom addresses were subsequently located, a final batch was conducted: batch 4) 96 melanoma survivors and 113 controls.

6.4 Data Collection

Study participants either completed the online questionnaire or mailed back the paper copy of the survey provided in the reminder mailing. A small number of participants reported not having a computer or having technical difficulties accessing the online survey and requested via telephone or email a paper copy of the survey (44 (3.8%) melanoma survivors and 32 (2.9%) controls). Other issues included individuals not remembering their original participation and wanting more information, confusion among controls about their purpose in a melanoma study, and those wanting to confirm questionnaire receipt. Two melanoma survivors reported that subsequent testing revealed they did not in fact have melanoma and therefore they did not feel it was appropriate to participate.

A separate REDCap database was created for data entry of the paper survey data. The first 20 each of melanoma survivors and controls were double entered and compared to identify common errors. Minimal differences were found, therefore due to time and budget constraints, the remaining surveys were not double entered.

6.5 Survey Response

For the purposes of this dissertation, surveys completed and returned by November 1, 2015 are reported. Approximately two-thirds of the surveys were completed online; the remaining were paper surveys (Table 7). The addition of the incentive increased the response. The response in the fourth batch was lower, likely due to the date cutoff rather than a difference in the participants.

The final response rate among eligible Skin Health Study participants was 60.7%, with 687 (63.9%) melanoma survivors and 624 (57.5%) controls completing the survey (Table 8). An additional five deaths (2 melanoma survivors and 3 controls) were reported by family. Despite all efforts, 53 (4.9%) eligible melanoma survivors and 83 (7.6%) eligible controls could not be located.

6.6 Analysis for Bias

To assess for selection bias, comparisons were made between those eligible and ineligible for the study and between those who did and did not participate in this follow-up survey using data from the original Skin Health Study (Table 9). Characteristics including sex, age, education, risk factors for melanoma (phenotypic risk score, family history of melanoma, sun exposure, sunburns, and sun protection practices), and among melanoma survivors, disease stage and tumor location, were considered.

Among the 2,268 participants in the Skin Health Study, 91 (4.0%) were determined to have died prior to the follow-up survey and 136 (6.0%) could not be located. Those who completed the survey were generally similar to those who did not respond, though they were older, more likely to have completed college, and less likely to

have ever used indoor tanning. When examined separately by melanoma survivors and controls, these differences were similar.

Table 6. Final eligibility status of Skin Health Study Participants.

	Cases (N=1167)		Controls (N=1101)	
Ineligible				
Known Deceased	73	6.3%	9	0.8%
Previous Refusal	0	0.0%	7	0.6%
Physician Reported Case Deceased	4	0.3%		
Physician Refused	15	1.3%		
Eligible				
Current Physician Not Found	225	19.3%		
Physician Consent –Active 1 st Fax	413	35.4%		
Physician Consent – Active 2 nd Fax	120	10.3%		
Physician Consent -Passive	317	27.2%		
Total Eligible to Contact	1075	92.1%	1085	98.5%

Table 7. Skin Health Study follow-up survey response rates by batch and type.

	Melanoma Survivors (N=1075)		Controls (N=1085)	
	N	%	N	%
Batch 1	90		90	
Online / no incentive	25	30.1	22	27.2
Paper / incentive	24	28.9	30	37.0
Non-Responders/Unable to Locate	34	41.0	29	35.8
<i>Located additional address (Batch 4)</i>	7		9	
Batch 2	510		510	
Online / incentive	229	49.3	189	41.8
Paper / no incentive	96	20.7	87	19.3
Non-Responders/Unable to Locate	139	30.0	175	38.8
<i>Located additional address (Batch 4)</i>	46		59	
Batch 3	475		485	
Online / incentive	178	41.2	167	38.0
Paper / no incentive	100	23.2	93	21.1
Non-Responders/Unable to Locate	154	35.6	180	40.9
<i>Located additional address (Batch 4)</i>	43		44	
Batch 4	96		113	
Online / incentive	22	23.0	28	24.7
Paper / no incentive	13	13.5	8	7.0
Non-Responders/Unable to Locate	61	63.5	77	71.3
Online	454	42.2	406	37.4
Paper	233	21.7	218	20.1
Total Surveys Completed	687	63.9	624	57.5

Table 8. Skin Health Study follow-up survey recruitment results among those determined to be eligible for contact.

	Cases (N=1075)		Controls (N=1085)	
	N	%	N	%
Unable to locate	53	4.9	83	7.6
Deceased	2	0.2	3	0.3
Refusal	8	0.7	17	1.6
Non-response	325	30.2	358	33.0
Survey Complete	687	63.9	624	57.5

Table 9. Characteristics of Skin Health Study Participants by Response to the Follow-up Survey.

	Original Skin Health Study (N=2268)		Died before 2015 Survey (N=91)		Unable to locate (N=136)		Non-respondents/ Refusal (N=730)		Respondents (N=1311)	
Characteristics	N	%	N	%	N	%	N	%	N	%
Case Status										
Case	1167	51.5	79	86.8	53	39.0	348	47.7	687	52.4
Control	1101	48.5	12	13.2	83	61.0	382	52.3	624	47.6
Sex										
Male	913	40.3	47	51.7	41	30.2	290	39.7	535	40.8
Female	1355	59.7	44	48.4	95	69.9	440	60.3	776	59.2
Age										
25-29 years	144	6.4	1	1.1	23	16.9	48	6.6	72	5.5
30-39 years	391	17.2	8	8.8	30	22.1	159	21.8	194	14.8
40-49 years	800	35.3	21	23.1	47	34.6	277	38.0	455	34.7
50-59 years	933	41.1	61	67.0	36	26.5	246	33.7	590	45.0
Completed college										
No	1222	53.9	57	62.6	73	54.1	449	61.5	643	49.1
Yes	1044	46.1	34	37.4	62	45.9	281	38.5	667	50.9
Missing	2		0		1		0		1	
Phenotypic Risk Index										
Low	712	31.7	25	28.4	41	30.8	230	31.8	416	31.9
Intermediate	972	43.2	33	37.5	61	45.9	317	43.8	561	43.1
High	564	25.1	30	34.1	31	23.3	177	24.5	326	25.0
Missing	20		3		3		6		8	
Family history of melanoma										
No	1789	80.3	76	84.4	103	77.3	576	80.3	1034	80.2
Yes	440	19.7	14	15.6	30	22.6	141	19.7	255	19.8
Missing	39		1		3		13		22	
Lifetime routine sun exposure										
Low	749	33.2	20	22.2	58	43.3	248	34.2	423	32.3
Medium	755	33.4	28	31.1	44	32.8	235	32.4	448	34.3
High	754	33.4	42	46.7	32	23.9	243	33.5	437	33.4
Missing	10		1		2		4		3	
Lifetime sun exposure from outdoor activities										
Low	754	33.3	19	21.1	47	34.6	257	35.3	431	32.9
Medium	755	33.4	29	32.2	49	36.0	243	33.4	434	33.1
High	755	33.4	42	46.7	40	29.4	228	31.3	445	34.0
Missing	4		1		0		2		1	

	Original Skin Health Study (N=2268)		Died before 2015 Survey (N=91)		Unable to locate (N=136)		Non-respondents/ Refusal (N=730)		Respondents (N=1311)	
Characteristics	N	%	N	%	N	%	N	%	N	%
Lifetime number of burns from sun										
None	101	4.5	2	2.2	8	5.9	37	5.1	54	4.1
1-2	389	17.2	16	17.6	28	20.6	125	17.2	220	16.8
3-5	439	19.4	14	16.5	30	22.1	145	19.9	249	19.0
>5	1334	59.0	59	63.7	70	51.5	421	57.8	785	60.0
<i>Missing</i>	5		0		0		2		3	
Ever use Indoor Tanning										
No	971	42.8	56	61.5	46	33.8	287	39.3	582	44.4
Yes	1297	57.2	35	38.5	90	66.2	443	60.7	729	55.6
Cases Only										
Disease Stage (MCSS)										
I	823	70.5	36	45.6	40	75.5	243	69.8	504	73.4
II	64	5.5	11	13.9	3	5.7	15	4.3	35	5.1
III/IV	70	6.0	24	30.4	2	3.8	17	4.9	27	3.9
Unknown	210	18.0	8	10.1	8	15.1	73	21.0	121	17.6
Tumor Location										
Head	138	11.8	12	15.2	4	7.6	44	12.6	78	11.4
Upper limb	289	24.8	12	15.2	11	20.8	91	26.2	175	25.5
Lower limb	311	26.7	20	25.3	17	32.1	87	25.0	187	27.2
Trunk	398	34.1	27	34.2	19	35.9	117	33.6	235	34.2
Unknown	21	2.7	8	10.1	2	3.8	9	2.6	12	1.8

7 Part II: Manuscript 2 - A cross-sectional survey of quality of life of long-term melanoma survivors compared to population controls

7.1 Introduction

As of 2014, over one million survivors of melanoma are living in the United States and this number continues to climb.¹ Unlike most cancer types, melanoma incidence has been increasing over the past 30 years, and the “melanoma epidemic”¹⁰ has shown little signs of trend reversal in the United States.^{11,12}

Change in quality of life (QOL) is a recognized major health outcome of cancer diagnosis and treatment, which may impact a patient’s prognosis, including survival.⁴⁵⁻⁴⁷ QOL incorporates three overlapping domains of function: physical, psychological, and social, as they relate to health status.⁴⁴ QOL can be significantly affected by pain, fatigue and other symptoms of cancer and treatment side effects.⁶

Melanoma survivors are a unique population to evaluate in terms of alteration of QOL related to their diagnosis or treatment, as it is one of the most common cancers in young adults and survivors remain at significant risk for tumor recurrence or for a second primary tumor. Data on QOL are available on those with advanced stage melanoma undergoing experimental treatments.⁵¹⁻⁶⁷ However little is known about specific survivorship issues faced by those with early stage disease, which make up the majority of melanoma survivors, or who have survived many years.⁶⁸ This is further complicated by the lack of control groups within studies with measured potential confounders, making it hard to conclude whether any changes in QOL are attributable to the melanoma diagnosis. A better understanding of the long-term effects of a melanoma diagnosis is

needed as clinicians and researchers develop appropriate follow-up care guidelines and create educational and other interventions aimed to improve the QOL of melanoma survivors.

7.2 Methods

7.2.1 Study Design and Population

See Chapter 6, section 6.1.

7.2.2 Identification of Eligible Participants

See Chapter 6, section 6.2.

7.2.3 Subject Recruitment

See Chapter 6, section 6.3.

7.2.4 Data Collection and Measures

See Chapter 6, section 6.4 for details on data collection.

QOL was measured in both melanoma survivors and controls using the Medical Outcomes Study Short Form 36 (SF-36) version 2, a generic measure that includes 36 items that can be summarized into the following subscales: Physical functional, Role limitations due to physical health, Role limitations due to emotional problems, Energy/fatigue, Emotional well-being, Social functioning, Pain, and General health.¹⁵² Standard scoring methods were used;¹⁵² however the scores were not standardized using population norms in order to compare means with other studies from different countries. Higher scores indicate better QOL. Reliability and validity of the instrument has been established for each of the eight scales with all reliability coefficients greater than 0.80.¹⁵²

Mental health was measured using the Hospital Anxiety and Depression Survey (HADS), an instrument which includes 14 items designed to assess anxiety and depression, each scored from 0-3.¹⁵⁴ While continuous total or subscale anxiety and depression scales can be calculated,¹⁵⁴ the proportions of individuals with potentially clinically meaningful depression and anxiety was used rather than means due to the fact that many survivors likely fall within the normal range. The maximum scores for depression and anxiety are 21 and an established cut-off of 8 for each scale is deemed potentially clinically relevant and recommended to identify persons who should be further screened for depression and/or anxiety.¹⁸⁷

Potential confounders, including demographics and comorbidities were collected. Assessment of co-morbidities, using questions from the ACS-SCS-II survey,¹⁷¹ included heart problems, hypertension, chronic back pain, arthritis, stroke, severe problems with memory or concentration, asthma/emphysema/chronic obstructive pulmonary disease, stomach and/or intestinal problems, diabetes, depression, anxiety, neuropathy, cancer, and other serious health conditions. The total number of co-morbidities was calculated for each participant. Updated information since participation in the original Skin Health Study was obtained, including education, income, marital status, body mass index, smoking status, and family history of melanoma.

Clinical characteristics of the melanoma diagnosis, including disease stage and location of tumor, when available, were provided by the Minnesota Cancer Surveillance System and supplemented with self-report survey data as needed.

7.2.5 Statistical Methods

For the purposes of this dissertation, 1311 (687 melanoma survivor and 624 control) surveys that were completed and returned by November 1, 2015 were included in the calculations of response rate. At the time of the analysis for this dissertation, data entry was complete for approximately 60% of those who returned paper surveys, resulting in complete data for 592 (86.2%) melanoma survivors and 518 (83.0%) controls.

Assessment of Bias

To assess how death and non-response may have biased the results, comparisons were made between those eligible and ineligible for the study and between those who did and did not participate in this follow-up survey using data from the original Skin Health Study as described in Chapter 6.6. Characteristics including sex, age, education, risk factors for melanoma (phenotype, family history of melanoma, sun exposure, sunburns, and sun protection practices), and among melanoma survivors, disease stage and tumor location, were considered.

Identification of Potential Confounding Factors

Demographic and general health characteristics were compared between melanoma survivors and population controls that completed the survey using Chi-squared tests. Controls who reported a history of melanoma (n=18; 3.4%) were excluded from the analysis. To confirm known confounding factors were present in this dataset, mean SF-36 subscale scores and depression and anxiety scores were compared across demographic and general health characteristics separately using univariate linear regression and logistic regression models, respectively.

Primary Analyses

Means \pm standard deviations (SD) and the effect sizes (Cohen's d ; difference in means divided by the standard deviation) are presented for the SF-36 subscales. It has been previously shown that effect sizes of 0.35-0.5 are clinically relevant for the SF-36 subscales.¹⁸⁸

Comparisons of the SF-36 subscale scores between melanoma survivors and population controls were conducted using multivariate linear regression models. Both sex and age-adjusted and fully-adjusted models were conducted and the difference in means and associated 95% confidence interval (CI) are presented. Potential confounders included in the final models were age at survey (continuous), sex, education (high school, vocation/associates, some college, college graduate, graduate/professional degree), income (<\$50,000, \$50,000-\$74,999, \$75,000-\$149,999, \$150,000+, prefer not to say), marital status (never married, married/partnered, widowed, divorced), body mass index (underweight/normal, overweight, obese), current smoking status (yes, no) and number of co-morbidities (0, 1, 2, 3, 4, 5+). The proportions of melanoma survivors and population controls with potentially clinically significant depression and/or anxiety were compared using multivariate logistic regression models with the same confounders listed above; odds ratios (OR) and 95% CI are presented.

To explore whether QOL between melanoma survivors and controls depended on age or sex, stratified analyses were conducted by age group (30-39, 40-49, 50-59, and 60-72) and by sex. Analyses were fully adjusted for all confounders, as previously described, and an interaction effect was included to examine whether a statistically

significant interaction between melanoma status and age or sex on QOL was present. Age was defined as age at time of survey (as opposed to age at diagnosis) so the data could be directly compared to other published data. Due to the number of statistical tests performed, p-values related to these primary analyses were adjusted to account for multiple comparisons using the Benjamini and Hochberg adjustment method;¹⁸⁹ adjusted p-values <0.05 were considered statistically significant.

Secondary Analyses

For the purposes of this dissertation, secondary analyses were conducted to determine whether particular subgroups of melanoma survivors had poorer QOL relative to controls. Analyses were conducted separately by melanoma stage (I, II, or III/IV), tumor site (head/neck, trunk, lower limb, upper limb), self-report of lymphedema, any report of adjuvant therapy for melanoma at time of either first diagnosis or recurrence, self-reported recurrence and/or metastasis, perceived seriousness of melanoma (lowest quartile, upper 75%), and fear of a second melanoma (below median, above median). Due to the exploratory nature of these analyses, p-values were not adjusted for multiple comparisons.

7.3 Results

7.3.1 Population Description and Assessment of Bias

See Chapter 6, sections 6.5 and 6.6 for details on survey response and assessment of bias.

Survey data related to QOL for 592 melanoma survivors and 518 controls were analyzed. Regardless of melanoma status, respondents were 55.8 ± 9.0 years old at time of

the survey, primarily female, white, highly educated, married, overweight or obese and likely to report at least one co-morbidity. Melanoma survivors and population controls were not statistically significantly different across the demographic and health characteristics (Table 10).

Melanoma survivors were diagnosed an average of 9.5 ± 1.1 years prior to completing the survey; the majority (86.5%) had stage I disease and received surgery only (Table 11). A minority had lymph node dissection (34.6%) and some (11.4%) reported lymphedema. Among the respondents, 20 (3.5%) reported a recurrence of their melanoma and 15 (2.6%) reported being diagnosed with metastatic disease since the original diagnosis.

7.3.2 Identification of Potential Confounding Factors

Age, sex, education, marital status, income, body mass index, smoking status, and each of the comorbidities were associated with the SF-36 subscales; race and family history of melanoma were not consistently associated, however (Tables 12a-12d). While these characteristics did not differ between melanoma survivors and population controls in this sample, they are associated with melanoma risk in the general population and were therefore included as potential confounders for all analyses.

7.3.3 Primary Analyses

Compared to population controls, melanoma survivors reported similar QOL measures across all SF-36 scales (Table 13). After adjustment for potential confounders, melanoma survivors had statistically significant but only modestly higher general health (76.1 ± 17.8 vs. 73.4 ± 18.5 , $p=0.04$), physical functioning (91.3 ± 14.8 vs. 87.9 ± 17.3 ,

$p=0.0004$, bodily pain (78.2 ± 20.6 vs. 73.1 ± 20.9 , $p=0.0009$), and physical role functioning (90.7 ± 17.0 vs. 87.6 ± 20.1 , $p=0.01$). These differences, however, did not reach the criterion for clinical significance as no scales had effect sizes exceeding 0.35. Further, no differences in the mental health, vitality, emotional role functioning or social role functioning subscales between melanoma survivors and controls were observed. Finally, no differences were observed in the proportion of melanoma survivors compared to controls with anxiety (16.1% vs. 19.0%, $p=0.53$) or depression (5.9% vs. 8.9%, $p=0.13$). It is noteworthy that melanoma survivors were less likely to report anxiety and depression compared to controls, though these differences were not statistically significant.

Evidence of potential differences in QOL for some of the SF-36 subscales was observed between melanoma survivors and controls according to their age at the time of the survey (Table 14a-d). For the general health and physical functioning subscales, interactions of melanoma status and age were statistically significant ($p=0.05$ and $p=0.02$, respectively). Specifically, melanoma survivors 50-59 years old reported statistically and clinically significantly better general health, physical functioning, bodily pain and physical role functioning QOL compared to population controls with effect sizes ranging from 0.35-0.44. These and all other SF-36 subscales were similar between melanoma survivors and controls in the other age groups (all effect sizes <0.35). In addition, while not statistically significant, melanoma survivors in the youngest age group reported potentially clinically meaningfully better QOL as measured by the bodily pain, mental health, vitality, emotional role functioning and social role functioning subscales (all

effect sizes > 0.40) compared to population controls. Finally, while variation in the odds ratios were observed for comparisons of rates of anxiety and depression between melanoma survivors and controls, none of the differences were statistically significant within the separate age groups.

QOL also did not appear to generally differ between melanoma patients and controls by sex (Tables 15a-b). Interestingly, male melanoma survivors had significantly better social role functioning compared to controls (93.2 ± 14.5 vs. 88.3 ± 19.7 , $p=0.002$) yet females did not (90.7 ± 16.0 vs. 89.5 ± 18.9 , $p=0.76$). While female melanoma survivors reported statistically significant better general health, physical functioning, bodily pain and physical role functioning compared to controls and the males did not, the effects were not clinically significant and were similar for both sexes.

7.3.4 Secondary Analyses

Subgroup analyses exploring the QOL of melanoma survivors according to stage, tumor location, lymphedema, adjuvant therapy and recurrence found most subgroups to have similar QOL as the population controls (Tables 16-22). Results should be cautiously interpreted due to the number of comparisons conducted.

Melanoma survivors with stage I disease were less likely to experience depression compared to controls (5.0% vs. 8.9%, $p=0.009$). Though not statistically significant, those with stage III/IV were more likely to report anxiety (26.3% vs. 19.0%, $p=0.26$) and depression (13.2% vs. 8.9%, $p=0.37$). In addition, while the measures of QOL were similar between melanoma survivors by tumor location and controls, those with melanoma tumors on their upper or lower limbs were less likely to report depression than

controls (3.3% vs. 8.9%, $p=0.02$ and 4.6% vs. 8.9%, $p=0.04$, respectively). Those who reported development of lymphedema, adjuvant therapy, and having recurrent or metastatic disease reported comparable QOL and mental health outcomes to controls. Comparisons of the QOL of melanoma survivors by their perceived seriousness of melanoma with population controls were similar as well, though those who perceived melanoma to be very serious were less likely to be depressed than controls (5.6% vs. 8.9%, $p=0.03$). Finally, melanoma survivors with less fear of a second melanoma had statistically significantly improved QOL compared to population controls for all SF-36 subscale measures, though none were clinically meaningful differences. They did, however, have lower rates of anxiety (7.2% vs. 19.0%, $p=0.0002$) and depression (2.5% vs. 8.9%, $p=0.002$) compared to controls. Survivors who reported higher fear of a second melanoma were, however, similar to controls for all measures.

7.4 Discussion

Long-term melanoma survivors participating in this cross-sectional study reported statistically significant but only modest differences in QOL compared to population controls. Melanoma survivors indicated potentially better physical QOL and no differences in emotional QOL compared to controls after adjustment for potential confounding factors. Other than superior physical QOL reported by melanoma survivors 50-59 years old and social role functioning in male melanoma survivors compared to similar controls, differences were not clinically meaningful. Our study suggests long-term melanoma survivors generally report similar QOL and mental health as population controls.

This is the largest study of melanoma survivors to date to compare long-term QOL and mental health to similarly recruited controls. Other studies have either 1) included melanoma survivors only with comparisons to general population norms (age and sex adjusted), and therefore, were unable to adjust for other confounding factors, or 2) were larger studies with healthy controls but included many cancer types of which melanoma survivors were a small minority and therefore had limited sample sizes and did not measure melanoma-specific potential confounding factors.

A few large studies of QOL among melanoma survivors in Europe, measured using the SF-36 or European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ 30), found similar QOL compared to age and sex adjusted population normative data.^{89-91,190} Specifically, a study in the Netherlands of 562 melanoma survivors, approximately five years post-diagnosis, found statistically significant better physical functioning, role functioning, emotional functioning, mental health, bodily pain, and general health compared to the population, however, the mean differences were not clinically significant.⁹¹ A study of 689 survivors in Germany, an average of eight years post-diagnosis, in contrast to our study, found evidence of poorer physical, emotional, cognitive and social function QOL measures in survivors compared to population norms.¹⁹⁰ These studies did not recruit control participants and therefore were unable to adjust for confounding factors. However, the results were generally similar to our study, indicating a melanoma diagnosis is not associated with poor physical or emotional QOL among long-term survivors.

A number of large studies have recruited cancer survivors, comprising numerous cancers including melanoma, and non-cancer controls. A study of long-term older individuals with and without cancer (average age of 74 years) in the United States found among the subgroup of melanoma survivors (n=80), survivors reported similar physical and emotional QOL as non-cancer controls.¹⁹¹ Another large study of short- and long-term cancer survivors and controls in the United States (including 153 with melanoma) also reported similar physical and emotional QOL between survivors and controls.¹⁹² An analysis of long-term cancer survivors in Australia, including 224 with melanoma, compared to 5,808 age and sex-matched respondents without a history of cancer reported melanoma survivors had statistically significantly better QOL outcomes than controls, though they were likely not clinically meaningful differences.

In our study, male and female survivors of melanoma were no different than their male or female counterparts in the control group on measures of physical and emotional QOL. Previous studies have found that females with melanoma report higher levels of distress, anxiety, and emotional stress than males.^{81,89-93} Interestingly, a large study of melanoma survivors found males were more likely to believe cancer had affected their overall health than females.⁸² In addition, studies exploring the relationship between age and QOL among melanoma survivors found younger survivors were more likely to experience emotional issues and older adults were more likely to experience more physical issues.^{82,95} The general lack of association with age and sex in our study is likely the result of comparison with appropriately matched controls and adjustment for potential confounding factors. Our data suggest previously reported differences among

melanoma survivors by age or sex may reflect differences in the general population rather than being specific to a melanoma diagnosis.

Reviews of studies of melanoma survivors, including long-term survivors, suggest up to one-third are in need of psychosocial support for distress, anxiety and depression,^{73,193} however studies to date either did not include a control group or compared measures using population normative data only. A systematic review and meta-analysis of depression and anxiety among long-term survivors of all cancers found rates of depression were similar to healthy controls but anxiety was elevated in cancer patients compared to healthy controls and this persisted for up to 10 years.⁷² While a number of studies have looked at depression and anxiety among patients diagnosed with melanoma, most have been conducted near the time of diagnosis.⁷³ Few studies have been conducted specifically looking at long-term melanoma survivors, though none included a similarly recruited control group.^{96,190,193,194} One study of 689 long-term melanoma survivors compared their results with the general population and found melanoma survivors reported significantly more depression.¹⁹⁰ These results are in contrast with our study findings that melanoma survivors appear to have similar rates of depression and anxiety as population controls.

Taken together, our findings are consistent with the growing literature on the effects of cancer on QOL, signifying that survivors of cancers with generally good prognoses return to physical and emotional health levels similar to the general population over time.^{6,8} It has been suggested that the act of surviving a cancer may even be associated with improved perception of QOL,⁹¹ which may explain why some outcomes

were higher in melanoma survivors compared to controls. In addition, the survivors who participated in this study had primarily early stage melanoma and therefore few received adjuvant therapy, which may contribute to the lack of differences in QOL. Further, these survivors were an average of 9.5 years post-diagnosis, meaning that any physical or emotional concerns at the time of diagnosis and treatment may have dissipated by the time of our study. Numerous studies have found increased distress among melanoma survivors at the time of diagnosis⁷³, however our data suggest this does not exceed rates of population controls once survivors are further from the diagnosis.

7.4.1 Study Limitations

This is largest study of both long-term melanoma survivors and similarly recruited controls to explore QOL to date; however, this study has limitations. As a cross-sectional study, data were obtained at a single time point and therefore baseline QOL data were not available. Though our data suggested participants were similar to those who did not participate, those diagnosed with melanoma with poorer QOL may have been those who died or did not respond.

In addition, comparisons between melanoma survivors and controls used generic QOL measures. Cancer- and melanoma-specific measures may be needed to ascertain long-term negative effects and concerns among melanoma survivors, however then comparisons with controls would not be possible.

While this is a population-based study, it was limited to those who lived in Minnesota at the time of their diagnosis and therefore may not be generalizable. In addition, although melanoma is most prevalent among non-Hispanic whites, these data do

not allow for an examination of possible differences in effects by race/ethnicity due to the fairly homogenous population.

7.4.2 Conclusion

In this large population-based cross-sectional study of long-term melanoma survivors and population controls, survivors reported similar physical and emotional general QOL as controls after adjustment for confounders. Consistent with data on other cancers, long-term melanoma survivors in this study, compared to controls, do not appear to have the need for an intervention focused on QOL. Further investigation using specific measures of QOL, however, are needed to determine if melanoma survivors experience certain challenges related to their diagnosis that would not be pertinent to controls. Overall, these data are encouraging for people diagnosed with melanoma, providers, and public health researchers alike as the number of melanoma survivors will continue to rise over the next few decades.

Table 10. Demographic and general health characteristics among melanoma survivors and population controls that completed the follow-up survey.

	Melanoma Survivors N=592		Population Controls N=518		
Variable	N	(%)	N	(%)	p-value
Age at survey					0.91
30-39	43	7.3	38	7.3	
40-49	101	17.1	81	15.6	
50-59	213	36.0	195	37.6	
60-72	235	39.7	204	39.4	
Sex					0.65
Female	351	59.3	314	60.6	
Male	241	40.7	204	39.4	
Race					0.007
White, Non-Hispanic	587	99.2	502	96.9	
Other	5	0.8	16	3.1	
Education					0.20
High school	65	11.4	55	10.9	
Vocational/Associates	95	16.7	107	21.2	
Some college	102	18.0	69	13.7	
College graduate	175	30.8	157	31.1	
Graduate/professional degree	131	23.1	117	23.2	
Missing	24		13		
Marital Status					0.56
Never married	27	4.8	27	5.3	
Married/Partnered	481	84.8	415	82.0	
Widowed	12	2.1	10	2.0	
Divorced	47	8.3	54	10.7	
Missing	24		13		
Income					0.14
<\$50,000	65	11.5	71	14.0	
\$50,000-74,999	94	16.6	93	18.4	
\$75,000-\$149,999	245	43.4	193	38.1	
\$150,000+	115	20.4	92	18.2	
Prefer not to say	46	8.4	57	11.3	
Missing	25		14		
Body Mass Index (BMI)					0.97
Underweight (<18.5 kg/m ²)	3	0.5	2	0.4	
Normal (18.5-24.9 kg/m ²)	227	38.3	204	39.4	
Overweight (25.0-29.9 kg/m ²)	202	34.1	178	34.5	
Obese (30.0+ kg/m ²)	160	27.0	134	25.9	
Current Smoker					0.06
No	558	94.7	468	91.9	
Yes	31	5.3	41	8.1	
Missing	3		9		
Family history of melanoma					0.99
No	406	68.6	355	68.5	
Yes	186	31.4	163	31.5	

	Melanoma Survivors N=592		Population Controls N=518		
Variable	N	(%)	N	(%)	p-value
Co-morbidities – Ever told you have...*					
Heart problems	68	11.8	61	12.1	0.88
Hypertension	202	34.9	155	30.6	0.14
Chronic Back Pain	116	20.0	123	24.3	0.09
Arthritis	165	28.5	165	32.7	0.14
Stroke	7	1.2	12	2.4	0.15
Severe problems with memory or concentration	8	1.4	9	1.8	0.60
Asthma, emphysema, or COPD	56	9.7	48	9.5	0.92
Stomach and/or intestinal problems	52	9.0	53	10.5	0.41
Diabetes	60	10.4	56	11.1	0.69
Depression resulting in treatment	128	22.1	116	23.0	0.73
Anxiety resulting in treatment	99	17.1	77	15.3	0.41
Neuropathy	35	6.0	34	6.7	0.64
Other mental health diagnosis	2	0.3	4	0.8	0.42
Autoimmune disease	7	1.2	7	1.4	0.77
Other skeletal issues	29	5.0	18	3.6	0.27
Thyroid issues	10	1.7	17	3.4	0.08
Cancer (excluding skin cancer)**	49	8.5	39	7.7	0.66
Non-melanoma skin cancer	29	5.0	26	5.1	0.93
Other serious health condition	38	6.7	30	6.0	0.65
Number of Co-morbidities***					0.85
None	139	23.7	120	23.7	
1	142	24.2	113	22.3	
2	127	21.6	107	21.2	
3	82	14.0	68	13.4	
4	49	8.4	46	9.1	
5+	48	8.2	52	10.3	

*missing for 26 participants (14 cases and 12 controls)

**controls with melanoma were removed from the analysis

***sum all comorbidities except non-melanoma skin cancer

Table 11. Disease characteristics among melanoma survivors (N=592).

Characteristic	N	%
Disease Stage		
I	475	86.5
II	35	6.4
III	31	5.7
IV	8	1.5
<i>Missing</i>	43	
Tumor Site		
Head/neck	63	10.8
Trunk	204	35.0
Arm	159	27.3
Leg	157	26.9
<i>Missing</i>	9	
Treatment Received (not exclusive)		
Surgery	569	99.1
Surgery including lymph nodes	193	34.6
Skin graft	43	7.7
Chemotherapy	7	1.3
Radiation therapy	6	1.1
Immunotherapy	27	4.8
Recurrence		
No	554	96.5
Yes	20	3.5
<i>Missing</i>	18	
Metastatic Disease		
No	559	97.4
Yes	15	2.6
<i>Missing</i>	18	
	N	Mean±SD
Time since diagnosis (years)	592	9.5±1.1

Table 12a. Association between SF-36 physical subscales and demographic and general health characteristics among all study participants.

	General Health (GH)			Physical functioning (PF)		
Variable	N	Mean±SD	p-value	N	Mean±SD	p-value
Age at survey			0.10			<0.0001
30-39	81	76.2±18.5		81	95.8±10.2	
40-49	174	76.1±17.8		175	94.3±13.3	
50-59	401	75.9±18.8		403	90.4±18.6	
60-72	431	73.2±17.6		430	84.9±20.5	
Sex			0.0006			0.37
Female	651	76.4±18.1		654	90.1±15.5	
Male	436	72.5±18.1		437	89.2±16.9	
Race			0.32			0.99
White, Non-Hispanic	1066	74.9±18.2		1070	89.7±16.1	
Other	21	71.0±13.4		21	89.7±15.2	
Education			0.005			<0.0001
High school	119	72.0±16.8		119	85.1±19.5	
Vocational/Associates	201	73.9±18.5		201	86.6±17.6	
Some college	171	71.7±21.8		170	86.6±19.7	
College graduate	331	76.5±16.4		331	92.4±12.7	
Graduate/professional degree	248	77.1±17.5		247	83.7±10.5	
Marital Status			0.03			0.02
Never married	53	67.8±20.5		53	88.1±18.2	
Married/Partnered	895	75.2±18.0		895	90.5±15.3	
Widowed	22	75.1±17.0		21	82.6±21.9	
Divorced	100	75.9±18.0		99	86.8±16.7	
Income			<0.0001			<0.0001
<\$50,000	134	69.8±19.7		134	80.2±21.7	
\$50,000-74,999	187	71.0±21.3		184	87.7±16.8	
\$75,000-\$149,999	437	76.1±16.6		438	91.2±14.1	
\$150,000+	207	79.3±16.4		207	95.7±8.0	
Prefer not to say	103	74.7±16.6		103	89.7±15.8	
Body Mass Index (BMI)			<0.0001			<0.0001
Normal (18.5-24.9 kg/m ²)*	424	79.4±16.8		423	93.9±12.0	
Overweight (25.0-29.9 kg/m ²)	373	75.4±16.1		378	91.3±12.9	
Obese (30.0+ kg/m ²)	290	67.4±20.1		290	81.6±21.3	
Current Smoker			0.002			0.0003
No	1015	75.3±18.0		1017	90.2±15.3	
Yes	70	68.5±19.4		72	83.1±23.7	
Family history of melanoma			0.50			0.17
No	740	75.1±18.0		745	89.3±16.9	
Yes	347	74.3±18.6		346	90.7±14.2	
Co-morbidities – Ever told you have...						
Heart problems	129	67.7±20.4	<0.0001	128	83.3±20.8	<0.0001
Hypertension	355	60.1±19.9	<0.0001	354	83.9±20.0	<0.0001
Chronic Back Pain	239	66.3±20.2	<0.0001	237	80.1±21.2	<0.0001
Arthritis	330	68.3±19.5	<0.0001	328	81.2±19.5	<0.0001
Stroke	19	61.4±20.4	0.001	19	75.8±24.1	0.0001
Severe problems with memory or concentration	17	53.9±31.5	<0.0001	17	65.0±32.5	<0.0001

	General Health (GH)			Physical functioning (PF)		
Variable	N	Mean±SD	p-value	N	Mean±SD	p-value
Asthma, emphysema, or COPD	104	66.4±23.0	<0.0001	104	83.2±21.3	<0.0001
Stomach and/or intestinal problems	105	62.2±22.1	<0.0001	104	82.5±20.7	<0.0001
Diabetes	115	61.9±21.5	<0.0001	116	77.5±24.3	<0.0001
Depression resulting in treatment	244	65.0±21.7	<0.0001	243	84.0±19.7	<0.0001
Anxiety resulting in treatment	176	65.4±21.5	<0.0001	175	84.5±21.2	<0.0001
Neuropathy	69	60.7±22.7	<0.0001	69	77.1±23.7	<0.0001
Other mental health diagnosis	6	45.8±23.7	<0.0001	6	74.2±26.7	0.02
Autoimmune disease	14	51.8±22.9	<0.0001	13	88.5±13.9	0.76
Other skeletal issues	47	69.7±17.0	0.05	47	83.0±17.3	0.003
Thyroid issues	27	70.0±20.9	0.17	27	79.8±19.2	0.0009
Cancer (excluding skin cancer)**	87	67.8±22.0	0.0001	86	84.7±19.9	0.002
Non-melanoma skin cancer	55	75.9±15.6	0.68	54	92.5±10.3	0.20
Other serious health condition	68	63.4±21.2	<0.0001	68	82.6±19.2	<0.0001
Number of Co-morbidities***			<0.0001			<0.0001
None	254	84.3±12.1		256	96.7±9.5	
1	254	79.9±13.1		255	94.0±10.4	
2	234	77.0±15.5		233	92.1±10.5	
3	149	68.1±18.0		149	86.2±16.1	
4	95	63.5±18.4		94	81.3±21.2	
5+	100	53.4±21.7		99	68.2±23.0	

*includes 5 participants who are underweight (BMI <18.5)

**controls with melanoma were removed from the analysis

***sum all comorbidities except non-melanoma skin cancer

Table 12b. Association between SF-36 physical subscales and demographic and general health characteristics among all study participants.

Variable	Bodily pain (BP)			Physical Role Functioning (RP)		
	N	Mean±SD	p-value	N	Mean±SD	p-value
Age at survey			<0.0001			<0.0001
30-39	81	82.4±20.6		81	95.3±13.4	
40-49	175	80.4±18.6		176	93.5±13.8	
50-59	403	76.7±21.3		403	91.1±14.9	
60-72	431	72.0±20.8		431	85.9±17.6	
Sex			0.19			0.01
Female	654	76.5±20.6		652	90.4±17.7	
Male	436	74.8±21.3		437	87.5±19.6	
Race			0.10			0.34
White, Non-Hispanic	1069	76.0±21.0		1068	89.3±18.5	
Other	21	68.4±18.4		21	85.4±20.4	
Education			0.001			<0.0001
High school	119	71.7±23.6		119	83.8±22.5	
Vocational/Associates	202	72.9±21.4		201	88.0±18.9	
Some college	171	73.9±22.6		170	84.7±23.1	
College graduate	332	78.5±19.8		331	92.1±15.7	
Graduate/professional degree	248	78.0±18.7		247	92.5±14.3	
Marital Status			0.15			0.25
Never married	54	74.7±24.0		53	87.3±21.7	
Married/Partnered	896	76.4±20.7		895	89.8±18.1	
Widowed	22	75.6±15.8		21	88.4±18.4	
Divorced	100	71.4±21.5		99	86.2±20.3	
Income			<0.0001			<0.0001
<\$50,000	135	66.9±24.6		134	78.7±26.2	
\$50,000-74,999	187	72.3±21.6		184	85.7±21.2	
\$75,000-\$149,999	438	77.6±19.9		438	91.3±16.0	
\$150,000+	207	80.8±18.7		207	94.6±11.3	
Prefer not to say	103	76.7±18.7		103	90.9±16.9	
Body Mass Index (BMI)			<0.0001			<0.0001
Normal (18.5-24.9 kg/m ²)*	425	80.7±18.3		423	93.2±13.8	
Overweight (25.0-29.9 kg/m ²)	375	76.1±20.2		377	90.0±16.9	
Obese (30.0+ kg/m ²)	290	68.4±23.2		289	82.6±24.1	
Current Smoker			0.0006			0.05
No	1017	76.5±20.5		1016	89.5±18.1	
Yes	71	67.6±24.4		71	85.0±24.0	
Family history of melanoma			0.69			0.65
No	743	75.7±21.2		743	89.1±19.0	
Yes	347	76.2±20.2		346	89.6±17.7	
Co-morbidities – Ever told you have...						
Heart problems	129	70.5±21.2	0.002	128	83.0±23.3	<0.0001
Hypertension	356	69.7±22.4	<0.0001	354	84.1±22.0	<0.0001
Chronic Back Pain	238	61.5±22.1	<0.0001	237	77.0±25.8	<0.0001
Arthritis	330	64.0±21.6	<0.0001	328	81.2±22.7	<0.0001
Stroke	19	68.1±26.2	0.10	19	77.6±30.4	0.005
Severe problems with memory or concentration	17	58.2±28.6	0.0004	17	61.0±38.9	<0.0001

	Bodily pain (BP)			Physical Role Functioning (RP)		
Variable	N	Mean±SD	p-value	N	Mean±SD	p-value
Asthma, emphysema, or COPD	104	67.2±23.3	<0.0001	104	82.0±23.5	<0.0001
Stomach and/or intestinal problems	105	63.1±24.4	<0.0001	104	79.6±25.7	<0.0001
Diabetes	116	67.1±23.8	<0.0001	116	77.0±26.4	<0.0001
Depression resulting in treatment	244	67.4±22.7	<0.0001	243	82.5±23.3	<0.0001
Anxiety resulting in treatment	175	68.9±24.3	<0.0001	175	84.0±23.4	<0.0001
Neuropathy	69	61.1±23.8	<0.0001	69	75.3±27.7	<0.0001
Other mental health diagnosis	6	54.2±26.6	0.01	6	60.4±42.0	0.0001
Autoimmune disease	14	64.1±16.5	0.03	13	86.5±22.7	0.58
Other skeletal issues	47	63.0±20.3	<0.0001	47	82.3±22.8	0.008
Thyroid issues	27	69.5±21.5	0.11	27	79.6±24.1	0.006
Cancer (excluding skin cancer)**	88	72.6±22.1	0.12	86	82.8±22.2	0.0006
Non-melanoma skin cancer	55	76.7±20.4	0.78	54	91.2±14.1	0.45
Other serious health condition	68	66.3±22.5	0.0001	68	75.1±25.4	<0.0001
Number of Co-morbidities***			<0.0001			<0.0001
None	256	87.5±13.9		255	97.1±8.2	
1	255	80.5±16.9		255	94.6±11.7	
2	234	75.9±19.4		233	90.9±14.8	
3	149	70.1±22.3		149	77.0±16.0	
4	95	65.9±21.4		94	79.7±22.6	
5+	100	51.9±19.6		99	66.2±26.9	

*includes 5 participants who are underweight (BMI <18.5)

**controls with melanoma were removed from the analysis

***sum all comorbidities except non-melanoma skin cancer

Table 12c. Association between SF-36 mental subscales and demographic and general health characteristics among all study participants.

Variable	Mental Health (MH)			Vitality (VT)		
	N	Mean±SD	p-value	N	Mean±SD	p-value
Age at survey			0.02			0.02
30-39	81	76.2±17.2		81	60.9±16.5	
40-49	174	79.1±14.0		174	66.0±16.1	
50-59	402	79.5±15.4		402	66.1±17.7	
60-72	429	81.4±13.6		430	67.2±16.5	
Sex			0.13			0.34
Female	650	79.4±14.9		650	79.4±14.9	
Male	436	80.7±14.4		437	66.7±16.5	
Race			0.11			0.41
White, Non-Hispanic	1065	80.0±14.7		1066	66.2±17.0	
Other	21	74.8±14.6		21	63.1±14.5	
Education			0.23			0.0001
High school	119	78.4±14.7		119	63.8±17.0	
Vocational/Associates	201	79.4±15.9		201	64.6±17.9	
Some college	171	78.6±15.6		171	62.8±19.3	
College graduate	330	80.6±14.1		331	66.9±16.2	
Graduate/professional degree	248	81.2±13.5		248	69.7±14.7	
Marital Status			0.0002			0.01
Never married	54	74.0±16.9		54	60.2±17.3	
Married/Partnered	893	80.7±14.0		894	66.5±17.0	
Widowed	22	82.3±10.2		22	72.7±7.8	
Divorced	100	75.9±17.8		100	64.5±17.3	
Income			0.0004			<0.0001
<\$50,000	135	75.8±17.6		135	61.4±18.6	
\$50,000-74,999	187	78.6±14.9		187	62.5±16.5	
\$75,000-\$149,999	436	80.2±14.3		437	66.8±16.8	
\$150,000+	207	82.4±12.2		207	70.1±15.0	
Prefer not to say	102	81.6±14.2		102	67.8±17.6	
Body Mass Index (BMI)			0.0005			<0.0001
Normal (18.5-24.9 kg/m ²)*	423	80.7±13.8		424	69.2±15.4	
Overweight (25.0-29.9 kg/m ²)	373	81.2±13.5		373	67.3±15.4	
Obese (30.0+ kg/m ²)	290	77.1±16.9		290	60.0±19.2	
Current Smoker			0.0005			0.001
No	1014	80.3±14.4		1015	66.5±16.8	
Yes	70	73.9±17.8		70	59.7±17.2	
Family history of melanoma			0.34			0.59
No	740	80.2±14.8		741	66.3±16.9	
Yes	346	79.3±14.5		346	65.7±17.1	
Co-morbidities – Ever told you have...						
Heart problems	129	80.1±14.9	0.87	129	63.9±19.9	0.10
Hypertension	354	78.1±15.3	0.004	354	62.1±18.2	<0.0001
Chronic Back Pain	239	75.8±16.3	<0.0001	239	58.5±18.8	<0.0001
Arthritis	329	78.9±15.4	0.14	329	62.2±17.9	<0.0001
Stroke	19	71.8±24.7	0.02	19	57.6±26.0	0.02
Severe problems with memory or concentration	17	61.2±22.6	<0.0001	17	40.8±26.5	<0.0001

	Mental Health (MH)			Vitality (VT)		
Variable	N	Mean±SD	p-value	N	Mean±SD	p-value
Asthma, emphysema, or COPD	104	77.1±16.6	0.04	104	60.1±19.5	0.0001
Stomach and/or intestinal problems	105	72.4±17.9	<0.0001	105	56.4±18.7	<0.0001
Diabetes	115	74.7±17.0	<0.0001	115	58.3±20.4	<0.0001
Depression resulting in treatment	244	69.3±18.3	<0.0001	244	55.4±19.7	<0.0001
Anxiety resulting in treatment	176	68.8±18.4	<0.0001	176	56.2±19.3	<0.0001
Neuropathy	69	73.0±18.6	<0.0001	69	55.7±22.2	<0.0001
Other mental health diagnosis	6	43.3±27.9	<0.0001	6	38.5±30.0	<0.0001
Autoimmune disease	14	74.7±13.7	0.19	14	55.8±17.2	0.02
Other skeletal issues	47	80.8±13.3	0.67	47	64.3±17.3	0.47
Thyroid issues	27	80.2±15.5	0.92	27	59.7±16.8	0.05
Cancer (excluding skin cancer)**	87	83.1±12.6	0.03	87	65.3±17.0	0.61
Non-melanoma skin cancer	55	81.5±12.6	0.43	55	67.7±14.3	0.48
Other serious health condition	68	75.2±17.5	0.006	68	61.4±18.2	0.02
Number of Co-morbidities***			<0.0001			<0.0001
None	254	83.3±12.0		255	71.8±14.6	
1	254	83.8±10.6		254	71.2±12.3	
2	233	80.3±14.6		233	66.9±15.9	
3	149	77.0±16.0		149	63.0±15.6	
4	95	76.3±16.2		95	58.2±17.9	
5+	100	68.2±18.6		100	48.8±20.7	

*includes 5 participants who are underweight (BMI <18.5)

**controls with melanoma were removed from the analysis

***sum all comorbidities except non-melanoma skin cancer

Table 12d. Association between SF-36 mental subscales and demographic and general health characteristics among all study participants.

Variable	Emotional Role Functioning (RE)			Social Role Functioning (SF)		
	N	Mean±SD	p-value	N	Mean±SD	p-value
Age at survey			0.30			0.24
30-39	81	91.3±17.4		81	88.1±19.4	
40-49	175	93.7±13.3		175	92.1±14.5	
50-59	403	81.8±16.8		405	89.7±19.0	
60-72	429	90.9±17.5		431	91.0±16.4	
Sex			0.76			0.43
Female	651	91.6±16.6		654	90.1±17.4	
Male	437	91.9±16.7		438	91.0±17.2	
Race			0.10			0.87
White, Non-Hispanic	1067	91.8±16.5		1071	90.5±17.3	
Other	21	85.7±22.4		21	89.9±20.4	
Education			0.03			<0.0001
High school	118	88.7±18.8		120	89.6±16.9	
Vocational/Associates	201	93.7±14.2		202	89.2±18.0	
Some college	170	89.5±17.8		171	85.2±22.1	
College graduate	331	92.5±16.4		332	92.5±15.9	
Graduate/professional degree	247	92.2±15.6		248	93.0±14.1	
Marital Status			0.05			0.0006
Never married	53	90.3±16.1		54	84.3±21.9	
Married/Partnered	894	92.3±16.2		896	91.3±16.5	
Widowed	21	89.7±17.5		22	93.2±10.7	
Divorced	99	87.7±17.5		101	85.6±21.6	
Income			<0.0001			<0.0001
<\$50,000	134	86.1±20.2		136	82.3±22.1	
\$50,000-74,999	184	89.9±17.9		187	88.8±19.0	
\$75,000-\$149,999	438	92.5±16.1		438	91.6±16.4	
\$150,000+	207	94.4±12.3		207	93.5±12.7	
Prefer not to say	102	94.1±14.2		103	93.4±15.9	
Body Mass Index (BMI)			0.0003			<0.0001
Normal (18.5-24.9 kg/m ²)*	423	93.1±14.2		425	91.6±15.6	
Overweight (25.0-29.9 kg/m ²)	376	92.7±15.3		377	92.6±14.7	
Obese (30.0+ kg/m ²)	289	88.4±20.7		290	86.1±21.7	
Current Smoker			0.002			<0.0001
No	1015	92.1±16.2		1019	91.0±16.9	
Yes	71	85.8±21.8		71	82.4±21.5	
Family history of melanoma			0.46			0.59
No	743	92.0±16.5		745	90.7±17.3	
Yes	345	91.2±17.0		347	90.1±17.5	
Co-morbidities – Ever told you have...						
Heart problems	128	89.8±17.3	0.15	129	88.1±19.3	0.10
Hypertension	353	89.3±19.1	0.0007	357	88.0±20.1	0.001
Chronic Back Pain	237	86.1±21.0	<0.0001	239	83.2±22.1	<0.0001
Arthritis	327	90.3±18.0	0.05	330	88.0±20.0	0.002
Stroke	19	79.4±28.6	0.0009	19	75.0±33.3	<0.0001
Severe problems with memory or concentration	17	59.3±28.8	<0.0001	17	59.6±31.1	<0.0001

	Emotional Role Functioning (RE)			Social Role Functioning (SF)		
Variable	N	Mean±SD	p-value	N	Mean±SD	p-value
Asthma, emphysema, or COPD	104	88.3±19.8	0.02	104	84.3±22.0	0.0001
Stomach and/or intestinal problems	104	86.1±21.8	0.0002	105	79.8±23.8	<0.0001
Diabetes	116	85.3±22.0	<0.0001	116	82.7±23.6	<0.0001
Depression resulting in treatment	243	79.6±23.0	<0.0001	244	80.2±23.2	<0.0001
Anxiety resulting in treatment	175	80.6±23.7	<0.0001	176	78.6±23.1	<0.0001
Neuropathy	69	83.3±23.3	<0.0001	69	78.6±23.5	<0.0001
Other mental health diagnosis	6	58.3±31.6	<0.0001	6	54.2±38.5	<0.0001
Autoimmune disease	13	89.7±12.3	0.68	14	81.3±18.8	0.05
Other skeletal issues	47	93.8±12.1	0.37	47	88.6±16.7	0.45
Thyroid issues	27	92.6±15.4	0.77	27	86.6±19.3	0.24
Cancer (excluding skin cancer)**	86	90.5±16.0	0.46	88	89.3±16.9	0.51
Non-melanoma skin cancer	54	91.5±16.1	0.92	55	92.0±13.7	0.49
Other serious health condition	68	83.9±21.9	<0.0001	68	83.1±25.3	0.0004
Number of Co-morbidities***			<0.0001			<0.0001
None	255	96.2±10.8		256	96.0±10.7	
1	255	96.6±9.8		255	96.0±9.1	
2	232	92.7±16.0		234	90.5±16.5	
3	149	88.4±17.7		150	87.5±19.5	
4	94	83.9±21.1		95	82.6±21.0	
5+	99	77.7±25.1		100	73.9±25.8	

*includes 5 participants who are underweight (BMI <18.5)

**controls with melanoma were removed from the analysis

***sum all comorbidities except non-melanoma skin cancer

Table 13. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls.

	Melanoma Survivors		Population Controls		Sex and age-adjusted		Full model*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	580	76.1±17.8	507	73.4±18.5	2.8 (0.7, 5.0)	0.01	2.5 (0.7, 4.3)	0.008	0.04	0.17
Physical functioning	588	91.3±14.8	503	87.9±17.3	3.5 (1.7, 5.4)	0.0002	3.5 (2.0, 5.1)	<0.0001	0.0004	0.28
Bodily pain	583	78.2±20.6	507	73.1±20.9	5.2 (2.7, 7.6)	<0.0001	4.4 (2.2, 6.6)	<0.0001	0.0009	0.25
Physical Role Functioning	586	90.7±17.0	503	87.6±20.1	3.2 (1.0, 5.3)	0.004	3.0 (1.1, 4.9)	0.002	0.01	0.19
Mental Health	580	80.6±14.5	506	79.1±14.8	1.4 (-0.3, 3.2)	0.11	1.1 (-0.6, 2.7)	0.21	0.33	0.08
Vitality	580	67.0±17.0	507	65.1±16.8	1.8 (-0.2, 3.9)	0.07	1.4 (-0.4, 3.2)	0.12	0.21	0.10
Emotional Role Functioning	585	92.2±16.0	503	91.1±17.4	1.1 (-0.9, 3.1)	0.26	1.0 (-0.9, 2.8)	0.29	0.44	0.07
Social Role Functioning	584	91.7±15.4	508	89.1±19.2	2.7 (0.6, 4.7)	0.01	2.3 (0.4, 4.2)	0.02	0.08	0.15
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.23		0.38	0.53	
Normal (<7)	481	83.9	410	81.0	1.00		1.00			
Borderline/ Abnormal (8+)	92	16.1	96	19.0	0.82 (0.60, 1.13)		0.86 (0.61, 1.20)			
HADS Depression – Categories						0.06		0.05	0.13	
Normal	543	94.1	462	91.1	1.00		1.00			
Borderline/ Abnormal (8+)	34	5.9	45	8.9	0.64 (0.40, 1.02)		0.59 (0.35, 1.00)			

* adjusted for sex, age, education, income, marital status, BMI category, smoking status and number of comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 14a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among those 30-39 years at time of survey.

AGE 30-39	Melanoma Survivors		Population Controls		Sex and age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	43	77.6±18.7	38	74.6±18.4	2.7 (-5.9, 11.4)	0.53	4.8 (-4.3, 14.0)	0.30	0.44	0.26
Physical functioning	43	93.8±17.6	38	97.0±5.9	-3.7 (-9.8, 2.5)	0.24	-0.2 (-4.5, 4.0)	0.91	0.94	0.03
Bodily pain	43	85.0±19.3	38	79.5±21.8	6.8 (-2.5, 16.1)	0.15	8.5 (-1.3, 18.2)	0.09	0.18	0.44
Physical Role Functioning	43	95.1±11.7	38	96.5±8.2	-2.3 (-6.9, 2.3)	0.33	-1.8 (-7.3, 3.7)	0.52	0.67	0.16
Mental Health	43	77.4±14.7	38	74.7±19.9	2.6 (-5.4, 10.5)	0.52	6.9 (-1.1, 14.8)	0.09	0.18	0.44
Vitality	43	63.2±14.0	38	58.2±18.8	4.7 (-2.9, 12.3)	0.22	7.1 (-1.7, 15.8)	0.11	0.21	0.41
Emotional Role Functioning	43	92.8±15.8	38	89.5±19.1	3.2 (-4.9, 11.3)	0.44	7.6 (0.0, 15.2)	0.05	0.13	0.51
Social Role Functioning	43	89.2±17.8	38	86.8±21.1	3.2 (-5.7, 12.1)	0.48	8.5 (-0.3, 17.3)	0.06	0.14	0.49
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.80		0.93	0.94	
Normal (<7)	29	67.4	25	65.8	1.00		1.00			
Borderline/ Abnormal (8+)	14	32.6	13	34.2	0.88 (0.34, 2.30)		0.94 (0.27, 3.26)			
HADS Depression – Categories						0.17		0.07	0.16	
Normal	40	93.0	31	81.6	1.00		1.00			
Borderline/ Abnormal (8+)	3	7.0	7	18.4	0.32 (0.06, 1.61)		0.11 (0.01, 1.18)			

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 14b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among those 40-49 years at time of survey.

AGE 40-49	Melanoma Survivors		Population Controls		Sex and age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	96	74.9±20.2	78	77.4±14.4	-2.2 (-7.6, 3.1)	0.41	-1.1 (-6.4, 4.1)	0.67	0.82	0.07
Physical functioning	98	93.3±15.0	78	93.7±12.2	-0.4 (-4.5, 3.7)	0.84	0.8 (-3.2, 4.7)	0.71	0.86	0.06
Bodily pain	97	80.9±19.8	78	79.6±17.1	1.2 (-4.4, 6.8)	0.68	2.4 (-3.4, 8.1)	0.42	0.57	0.13
Physical Role Functioning	97	93.8±15.2	78	95.0±10.7	-0.9 (-4.9, 3.0)	0.64	0.3 (-3.7, 4.3)	0.88	0.94	0.02
Mental Health	96	78.7±15.1	78	79.5±12.6	-0.7 (-5.0, 3.5)	0.73	-0.6 (-5.0, 3.8)	0.79	0.92	0.04
Vitality	96	64.0±18.5	78	68.5±12.2	-4.5 (-9.3, 0.4)	0.07	-4.2 (-9.3, 0.8)	0.10	0.19	0.27
Emotional Role Functioning	97	93.1±14.3	78	94.4±11.7	-1.2 (-5.2, 2.8)	0.55	-0.7 (-4.9, 3.5)	0.74	0.88	0.05
Social Role Functioning	97	91.4±15.2	78	92.9±13.5	-1.5 (-5.8, 2.7)	0.48	-1.9 (-6.3, 2.6)	0.40	0.55	0.14
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.62		0.36	0.51	
Normal (<7)	71	74.7	60	77.9	1.00		1.00			
Borderline/ Abnormal (8+)	24	25.3	17	22.1	1.20 (0.59, 2.45)		1.48 (0.64, 3.43)			
HADS Depression – Categories						0.08		0.15	0.25	
Normal	87	90.6	76	97.4	1.00		1.00			
Borderline/ Abnormal (8+)	9	9.4	2	2.6	4.21 (0.84, 20.96)		3.54 (0.63, 19.89)			

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 14c. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among those 50-59 years at time of survey.

AGE 50-59	Melanoma Survivors		Population Controls		Sex and age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	210	79.5±16.5	191	71.9±20.3	7.5 (3.9, 11.2)	<0.0001	6.9 (3.5, 10.3)	<0.0001	0.0009	0.41
Physical functioning	213	94.0±11.3	190	87.8±17.5	6.2 (3.3, 9.1)	<0.0001	5.8 (3.2, 8.5)	<0.0001	0.0007	0.44
Bodily pain	212	81.0±20.0	191	72.0±21.8	8.8 (4.7, 12.9)	<0.0001	8.1 (4.1, 12.0)	<0.0001	0.0009	0.42
Physical Role Functioning	213	93.5±14.2	190	87.0±22.0	6.4 (2.8, 10.0)	0.0006	5.9 (2.5, 9.4)	0.0009	0.007	0.35
Mental Health	211	80.1±15.7	191	78.8±15.0	1.0 (-2.0, 4.1)	0.50	-0.2 (-3.2, 2.8)	0.89	0.94	0.01
Vitality	211	68.5±17.1	191	63.4±17.9	4.8 (1.3, 8.2)	0.007	3.8 (0.5, 7.2)	0.02	0.08	0.23
Emotional Role Functioning	213	92.3±16.8	190	91.3±16.8	0.8 (-2.5, 4.1)	0.64	-0.2 (-3.5, 3.0)	0.89	0.94	0.01
Social Role Functioning	213	91.5±16.9	192	87.7±20.9	3.6 (-0.1, 7.3)	0.06	2.8 (-0.8, 6.5)	0.12	0.21	0.16
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.03		0.06	0.14	
Normal (<7)	182	87.5	150	78.5	1.00		1.00			
Borderline/ Abnormal (8+)	26	12.5	41	21.5	0.54 (0.32, 0.93)		0.58 (0.32, 1.02)			
HADS Depression – Categories						0.11		0.22	0.34	
Normal	197	93.8	170	89.0	1.00		1.00			
Borderline/ Abnormal (8+)	13	6.2	21	11.0	0.56 (0.27, 1.15)		0.59 (0.26, 1.37)			

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 14d. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among those 60-72 years at time of survey.

AGE 60-72	Melanoma Survivors		Population Controls		Sex and age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	231	73.3±17.2	200	73.0±18.0	0.4 (-3.0, 6.7)	0.83	0.3 (-2.9, 3.5)	0.86	0.94	0.02
Physical functioning	234	87.6±16.2	197	83.9±18.9	4.1 (0.9, 7.3)	0.01	4.5 (1.5, 7.5)	0.003	0.02	0.30
Bodily pain	231	73.4±20.9	200	70.5±20.6	3.1 (-0.9, 7.0)	0.13	3.0 (-0.7, 6.7)	0.12	0.21	0.16
Physical Role Functioning	233	86.0±19.6	197	83.6±21.5	2.8 (-1.1, 6.6)	0.16	3.4 (-0.2, 7.0)	0.07	0.16	0.19
Mental Health	230	82.4±12.9	199	80.1±14.3	2.3 (-0.3, 4.8)	0.09	2.6 (0.07, 5.1)	0.04	0.12	0.20
Vitality	230	67.6±16.6	200	66.7±16.4	0.9 (-2.2, 4.1)	0.56	0.9 (-2.2, 3.9)	0.58	0.74	0.05
Emotional Role Functioning	232	91.7±15.9	197	89.9±19.2	2.0 (-1.3, 5.3)	0.23	2.9 (-0.4, 6.1)	0.08	0.17	0.18
Social Role Functioning	231	92.5±13.5	200	89.3±19.0	3.4 (0.3, 6.5)	0.03	3.6 (0.6, 6.6)	0.02	0.08	0.23
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.97		0.94	0.94	
Normal (<7)	199	87.7	175	87.5	1.00		1.00			
Borderline/ Abnormal (8+)	28	12.3	25	12.5	1.01 (0.57, 1.81)		1.02 (0.56, 1.88)			
HADS Depression – Categories						0.12		0.08	0.17	
Normal	219	96.1	185	92.5	1.00		1.00			
Borderline/ Abnormal (8+)	2	4.0	15	7.5	0.51 (0.22, 1.19)		0.44 (0.18, 1.09)			

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 15a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among males.

MALES	Melanoma Survivors		Population Controls		Age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	238	73.4±18.2	198	71.6±18.0	1.8 (-1.6, 5.2)	0.31	2.1 (-1.1, 5.3)	0.21	0.33	0.13
Physical functioning	240	90.1±16.4	197	88.1±17.5	2.0 (-1.2, 5.1)	0.22	3.2 (0.5, 5.9)	0.02	0.08	0.23
Bodily pain	238	76.4±21.4	198	72.9±21.1	3.4 (-0.6, 7.3)	0.10	3.8 (0.1, 7.5)	0.04	0.12	0.20
Physical Role Functioning	240	88.7±18.8	197	86.1±20.5	2.5 (-1.1, 6.1)	0.18	3.8 (0.4, 7.2)	0.03	0.11	0.22
Mental Health	239	81.8±14.0	197	79.4±14.8	2.5 (-0.2, 5.2)	0.07	2.8 (0.2, 5.5)	0.04	0.12	0.21
Vitality	239	67.1±17.4	198	66.2±15.5	0.9 (-2.2, 4.0)	0.57	1.2 (-1.8, 4.2)	0.44	0.58	0.08
Emotional Role Functioning	240	92.7±15.4	197	90.9±18.1	1.8 (-1.4, 4.9)	0.27	3.0 (-0.1, 6.0)	0.06	0.14	0.19
Social Role Functioning	239	93.2±14.5	199	88.3±19.7	4.9 (1.7, 8.1)	0.003	5.9 (2.8, 9.0)	0.0002	0.002	0.37
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.08		0.05	0.13	
Normal (<7)	208	88.5	164	82.8	1.00		1.00			
Borderline/ Abnormal (8+)	27	11.5	34	17.2	0.62 (0.36, 1.07)		0.56 (0.31, 1.01)			
HADS Depression – Categories						0.13		0.04	0.12	
Normal	223	93.7	178	89.9	1.00		1.00			
Borderline/ Abnormal (8+)	15	6.3	20	10.1	0.58 (0.28, 1.17)		0.43 (0.19, 0.97)			

* adjusted for age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 15b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors and population controls among females.

FEMALES	Melanoma Survivors		Population Controls		Age-adjusted		Fully adjusted*			
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Diff Means (95% CI)	p-value	Adj p-value**	Effect Size ⁺
General health	342	78.0±17.2	309	74.6±18.8	3.5 (0.7, 6.2)	0.01	3.3 (0.7, 6.0)	0.01	0.05	0.20
Physical functioning	348	92.2±13.5	306	87.8±17.2	4.6 (2.3, 6.9)	<0.0001	4.5 (2.4, 6.6)	<0.0001	0.0009	0.33
Bodily pain	345	79.5±20.0	309	73.3±20.9	6.4 (3.3, 9.5)	<0.0001	5.6 (2.7, 8.6)	0.0002	0.002	0.30
Physical Role Functioning	346	92.0±15.4	306	88.6±19.9	3.6 (1.0, 6.3)	0.007	3.5 (0.9, 6.1)	0.008	0.04	0.21
Mental Health	341	79.7±14.8	309	78.9±14.9	0.7 (-1.5, 3.0)	0.52	0.2 (-2.0, 2.5)	0.83	0.94	0.02
Vitality	341	66.9±16.7	309	64.4±17.6	-2.4 (-0.2, 5.1)	0.07	2.0 (-0.5, 4.6)	0.12	0.21	0.12
Emotional Role Functioning	345	91.9±16.4	306	91.2±16.9	0.7 (-1.9, 3.3)	0.59	0.2 (-2.3, 2.7)	0.88	0.94	0.01
Social Role Functioning	345	90.7±16.0	309	89.5±18.9	1.2 (-1.5, 3.8)	0.40	0.7 (-1.9, 3.3)	0.61	0.76	0.04
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**	
HADS Anxiety – Categories						0.83		0.92	0.94	
Normal (<7)	273	80.8	246	79.9	1.00		1.00			
Borderline/ Abnormal (8+)	65	19.2	62	20.1	0.96 (0.65, 1.42)		1.02 (0.68, 1.54)			
HADS Depression – Categories						0.21		0.30	0.44	
Normal	320	94.4	284	91.9	1.00		1.00			
Borderline/ Abnormal (8+)	19	5.6	25	8.1	0.68 (0.36, 1.25)		0.71 (0.37, 1.36)			

* adjusted for age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

⁺ Cohen's d; difference in means divided by the standard deviation

Table 16a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with Stage I disease and population controls.

	Stage I		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	466	76.4±17.9	507	73.4±18.5	3.2 (1.0, 5.4)	0.004	0.19
Physical functioning (PF)	471	91.4±15.3	503	87.9±17.3	3.9 (2.1, 5.7)	<0.0001	0.28
Bodily pain (BP)	468	79.2±20.0	507	73.1±20.9	5.9 (3.4, 8.3)	<0.0001	0.31
Physical Role Functioning (RP)	470	91.3±16.6	503	87.6±20.1	4.1 (1.9, 6.3)	0.0002	0.24
Mental Health (MH)	466	81.2±13.8	506	79.1±14.8	1.9 (0.2, 3.7)	0.03	0.14
Vitality (VT)	466	67.5±17.0	507	65.1±16.8	2.3 (0.2, 4.3)	0.03	0.14
Emotional Role Functioning (RE)	469	93.2±14.3	503	91.1±17.4	2.4 (0.4, 4.4)	0.02	0.16
Social Role Functioning (SF)	469	92.4±14.9	508	89.1±19.2	3.4 (1.2, 5.5)	0.002	0.20
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.14	
Normal (<7)	390	84.6	410	81.0	1.00		
Borderline/Abnormal (8+)	71	15.4	96	19.0	0.77 (0.54, 1.10)		
HADS Depression – Categories*						0.009	
Normal	441	95.0	462	91.1	1.00		
Borderline/Abnormal (8+)	23	5.0	45	8.9	0.47 (0.27, 0.83)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 16b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with Stage II disease and population controls.

SF-36 Subscale	Stage II		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	35	76.2±16.9	507	73.4±18.5	2.5 (-3.4, 8.5)	0.41	0.07
Physical functioning (PF)	35	93.0±10.1	503	87.9±17.3	4.5 (-0.7, 9.7)	0.09	0.15
Bodily pain (BP)	35	76.2±22.4	507	73.1±20.9	2.9 (-3.9, 9.6)	0.40	0.07
Physical Role Functioning (RP)	35	88.6±19.1	503	87.6±20.1	0.6 (-5.8, 7.0)	0.85	0.02
Mental Health (MH)	35	80.7±13.4	506	79.1±14.8	2.5 (-3.9, 5.9)	0.68	0.04
Vitality (VT)	35	67.0±14.3	507	65.1±16.8	1.1 (-4.4, 6.5)	0.70	0.03
Emotional Role Functioning (RE)	35	90.2±17.6	503	91.1±17.4	-1.1 (-6.9, 4.7)	0.71	0.03
Social Role Functioning (SF)	35	92.5±13.3	508	89.1±19.2	3.1 (-3.2, 9.3)	0.33	0.08
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.41	
Normal (<7)	30	88.2	410	81.0	1.00		
Borderline/Abnormal (8+)	4	11.8	96	19.0	0.63 (0.21, 1.91)		
HADS Depression – Categories*						0.25	
Normal	34	97.1	462	91.1	1.00		
Borderline/Abnormal (8+)	1	2.9	45	8.9	0.30 (0.04, 2.36)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 16c. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with Stage III/IV disease and population controls.

SF-36 Subscale	Stage III/IV		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	38	73.4±14.1	507	73.4±18.5	0.0 (-5.9, 5.8)	0.99	0.00
Physical functioning (PF)	39	91.4±10.6	503	87.9±17.3	4.7 (-0.3, 9.7)	0.07	0.16
Bodily pain (BP)	39	69.9±24.4	507	73.1±20.9	-2.9 (-9.6, 3.7)	0.38	0.08
Physical Role Functioning (RP)	39	86.9±17.9	503	87.6±20.1	0.1 (-6.1, 6.3)	0.98	0.00
Mental Health (MH)	38	78.3±18.2	506	79.1±14.8	-1.0 (-6.0, 4.0)	0.69	0.04
Vitality (VT)	38	63.7±17.4	507	65.1±16.8	-0.5 (-6.0, 4.9)	0.85	0.02
Emotional Role Functioning (RE)	39	85.3±24.1	503	91.1±17.4	-4.8 (-10.7, 1.0)	0.11	0.14
Social Role Functioning (SF)	39	87.2±19.3	508	89.1±19.2	-1.5 (-7.7, 4.8)	0.65	0.04
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.26	
Normal (<7)	28	73.7	410	81.0	1.00		
Borderline/Abnormal (8+)	10	26.3	96	19.0	1.59 (0.71, 3.59)		
HADS Depression – Categories*						0.37	
Normal	33	86.8	462	91.1	1.00		
Borderline/Abnormal (8+)	5	13.2	45	8.9	1.63 (0.56, 4.75)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 17a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with melanoma on head/neck and population controls.

	Head/Neck		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size⁺
General health (GH)	62	78.0±17.5	507	73.4±18.5	5.3 (0.7, 9.8)	0.02	0.19
Physical functioning (PF)	63	90.9±13.9	503	87.9±17.3	4.5 (0.5, 8.5)	0.03	0.19
Bodily pain (BP)	62	77.0±21.3	507	73.1±20.9	5.3 (0.1, 10.5)	0.04	0.17
Physical Role Functioning (RP)	63	89.4±17.8	503	87.6±20.1	4.2 (-0.6, 9.1)	0.09	0.15
Mental Health (MH)	62	81.0±13.7	506	79.1±14.8	1.7 (-2.1, 5.5)	0.38	0.08
Vitality (VT)	62	69.0±14.5	507	65.1±16.8	4.4 (0.2, 8.6)	0.04	0.18
Emotional Role Functioning (RE)	63	94.0±11.7	503	91.1±17.4	4.1 (-0.3, 8.4)	0.07	0.16
Social Role Functioning (SF)	62	93.1±13.9	508	89.1±19.2	5.2 (0.4, 10.0)	0.03	0.18
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.23	
Normal (<7)	54	87.1	410	81.0	1.00		
Borderline/Abnormal (8+)	8	12.9	96	19.0	0.61 (0.27, 1.38)		
HADS Depression – Categories*						0.19	
Normal	59	95.2	462	91.1	1.00		
Borderline/Abnormal (8+)	3	4.8	45	8.9	0.43 (0.12, 1.53)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 17b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with melanoma on trunk and population controls.

SF-36 Subscale	Trunk		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	200	74.3±19.2	507	73.4±18.5	1.6 (-1.3, 4.5)	0.28	0.08
Physical functioning (PF)	203	89.9±17.2	503	87.9±17.3	3.2 (0.8, 5.7)	0.01	0.20
Bodily pain (BP)	200	77.0±21.9	507	73.1±20.9	3.6 (0.3, 6.9)	0.03	0.17
Physical Role Functioning (RP)	202	89.7±18.1	503	87.6±20.1	2.5 (-0.5, 5.6)	0.10	0.13
Mental Health (MH)	200	79.7±16.2	506	79.1±14.8	0.8 (-1.7, 3.2)	0.53	0.05
Vitality (VT)	200	64.9±18.6	507	65.1±16.8	0.1 (-2.6, 2.8)	0.94	0.01
Emotional Role Functioning (RE)	202	91.0±19.4	503	91.1±17.4	0.6 (-2.3, 3.4)	0.71	0.03
Social Role Functioning (SF)	201	90.3±18.1	508	89.1±19.2	1.2 (-1.9, 4.2)	0.45	0.06
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.72	
Normal (<7)	159	81.5	410	81.0	1.00		
Borderline/Abnormal (8+)	36	18.5	96	19.0	0.92 (0.58, 1.46)		
HADS Depression – Categories*						0.87	
Normal	180	90.5	462	91.1	1.00		
Borderline/Abnormal (8+)	19	9.6	45	8.9	1.05 (0.57, 1.93)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 17c. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with melanoma on upper limbs and population controls.

	Upper limbs		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size⁺
General health (GH)	156	76.0±15.9	507	73.4±18.5	2.9 (-0.2, 6.0)	0.07	0.14
Physical functioning (PF)	159	91.7±13.3	503	87.9±17.3	5.1 (2.5, 7.7)	0.0001	0.31
Bodily pain (BP)	158	77.6±19.3	507	73.1±20.9	5.5 (2.1, 9.0)	0.002	0.25
Physical Role Functioning (RP)	158	91.9±15.5	503	87.6±20.1	5.5 (2.3, 8.7)	0.0007	0.27
Mental Health (MH)	156	81.1±14.0	506	79.1±14.8	1.7 (-0.9, 4.3)	0.19	0.10
Vitality (VT)	156	67.4±16.8	507	65.1±16.8	1.9 (-1.0, 4.9)	0.20	0.10
Emotional Role Functioning (RE)	157	92.3±14.3	503	91.1±17.4	1.4 (-1.5, 4.3)	0.35	0.07
Social Role Functioning (SF)	158	93.8±12.8	508	89.1±19.2	5.1 (1.9, 8.2)	0.002	0.25
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.08	
Normal (<7)	136	88.3	410	81.0	1.00		
Borderline/Abnormal (8+)	18	11.7	96	19.0	0.61 (0.35, 1.06)		
HADS Depression – Categories*						0.02	
Normal	149	96.8	462	91.1	1.00		
Borderline/Abnormal (8+)	5	3.3	45	8.9	0.27 (0.09, 0.79)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 17d. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with melanoma on lower limbs and population controls.

	Lower limbs		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size⁺
General health (GH)	153	77.5±17.8	507	73.4±18.5	4.0 (0.7, 7.2)	0.02	0.19
Physical functioning (PF)	154	92.7±13.3	503	87.9±17.3	4.0 (1.2, 6.7)	0.005	0.23
Bodily pain (BP)	154	80.6±20.3	507	73.1±20.9	6.3 (2.7, 9.9)	0.0007	0.27
Physical Role Functioning (RP)	154	90.9±16.9	503	87.6±20.1	2.9 (-0.5, 6.3)	0.09	0.14
Mental Health (MH)	153	80.6±13.2	506	79.1±14.8	1.3 (-1.4, 3.9)	0.35	0.07
Vitality (VT)	153	67.9±16.0	507	65.1±16.8	2.8 (-0.1, 5.8)	0.06	0.15
Emotional Role Functioning (RE)	154	92.5±14.5	503	91.1±17.4	1.2 (-1.8, 4.3)	0.42	0.06
Social Role Functioning (SF)	154	90.7±14.8	508	89.1±19.2	1.4 (-1.8, 4.7)	0.38	0.07
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						1.00	
Normal (<7)	124	81.1	410	81.0	1.00		
Borderline/Abnormal (8+)	29	19.0	96	19.0	1.00 (0.61, 1.63)		
HADS Depression – Categories*						0.04	
Normal	146	95.4	462	91.1	1.00		
Borderline/Abnormal (8+)	7	4.6	45	8.9	0.39 (0.17, 0.94)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 18. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with lymphedema and population controls.

SF-36 Subscale	Lymphedema		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	22	72.0±15.8	507	73.4±18.5	-2.6 (-10.0, 4.8)	0.48	0.06
Physical functioning (PF)	22	92.0±11.3	503	87.9±17.3	3.0 (-3.5, 9.5)	0.36	0.08
Bodily pain (BP)	22	71.2±26.8	507	73.1±20.9	-3.1 (-11.6, 5.4)	0.47	0.06
Physical Role Functioning (RP)	22	88.4±15.2	503	87.6±20.1	-0.7 (-8.7, 7.2)	0.85	0.02
Mental Health (MH)	22	77.3±16.3	506	79.1±14.8	-2.6 (-8.8, 3.6)	0.41	0.07
Vitality (VT)	22	64.0±16.9	507	65.1±16.8	-2.4 (-9.2, 4.5)	0.49	0.06
Emotional Role Functioning (RE)	22	86.4±18.6	503	91.1±17.4	-5.1 (-12.4, 2.1)	0.17	0.12
Social Role Functioning (SF)	22	89.2±15.1	508	89.1±19.2	-1.1 (-9.0, 6.8)	0.78	0.02
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.47	
Normal (<7)	17	77.3	410	81.0	1.00		
Borderline/Abnormal (8+)	5	22.7	96	19.0	1.48 (0.51, 4.33)		
HADS Depression – Categories*						0.62	
Normal	20	91.9	462	91.1	1.00		
Borderline/Abnormal (8+)	2	9.1	45	8.9	1.48 (0.31, 7.01)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 19. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors who had any adjuvant therapy (chemotherapy, radiation or immunotherapy at time of initial or recurrent disease) and population controls.

SF-36 Subscale	Any Adjuvant Therapy		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	34	76.0±14.1	507	73.4±18.5	-2.6 (-3.4, 8.6)	0.40	0.07
Physical functioning (PF)	35	93.0±9.8	503	87.9±17.3	6.4 (1.2, 11.7)	0.02	0.21
Bodily pain (BP)	35	76.5±21.4	507	73.1±20.9	4.0 (-2.6, 10.8)	0.24	0.10
Physical Role Functioning (RP)	35	88.8±16.4	503	87.6±20.1	2.4 (-4.1, 8.8)	0.47	0.06
Mental Health (MH)	35	79.6±14.8	506	79.1±14.8	0.3 (-4.7, 5.3)	0.90	0.01
Vitality (VT)	35	67.0±13.7	507	65.1±16.8	2.4 (-3.1, 7.9)	0.39	0.08
Emotional Role Functioning (RE)	35	90.0±16.5	503	91.1±17.4	-0.6 (-6.4, 5.3)	0.85	0.02
Social Role Functioning (SF)	35	93.2±13.0	508	89.1±19.2	3.2 (-1.9, 10.7)	0.17	0.12
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.87	
Normal (<7)	28	80.0	410	81.0	1.00		
Borderline/Abnormal (8+)	7	20.0	96	19.0	1.08 (0.43, 2.70)		
HADS Depression – Categories*						0.22	
Normal	34	97.1	462	91.1	1.00		
Borderline/Abnormal (8+)	1	2.9	45	8.9	0.27 (0.03, 2.19)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 20. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors with recurrence or metastases and population controls.

SF-36 Subscale	Recurrence or Metastases		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	27	73.6±15.8	507	73.4±18.5	0.4 (-6.5, 7.2)	0.91	0.01
Physical functioning (PF)	28	91.6±11.5	503	87.9±17.3	4.1 (-1.8, 10.0)	0.18	0.12
Bodily pain (BP)	28	76.5±26.6	507	73.1±20.9	3.5 (-4.2, 11.3)	0.37	0.08
Physical Role Functioning (RP)	28	88.8±16.0	503	87.6±20.1	2.0 (-5.2, 9.2)	0.59	0.05
Mental Health (MH)	27	78.7±17.2	506	79.1±14.8	-0.4 (-6.1, 5.4)	0.91	0.01
Vitality (VT)	27	64.1±18.1	507	65.1±16.8	-0.8 (-5.5, 7.2)	0.80	0.02
Emotional Role Functioning (RE)	27	91.4±15.8	503	91.1±17.4	3.4 (-6.2, 7.2)	0.89	0.01
Social Role Functioning (SF)	28	88.4±18.0	508	89.1±19.2	-0.2 (-7.4, 7.0)	0.96	0.00
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.96	
Normal (<7)	21	77.8	410	81.0	1.00		
Borderline/Abnormal (8+)	6	22.2	96	19.0	1.03 (0.38, 2.79)		
HADS Depression – Categories*						0.21	
Normal	26	96.3	462	91.1	1.00		
Borderline/Abnormal (8+)	1	3.7	45	8.9	0.26 (0.03, 2.14)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 21a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors who report melanoma to be not very serious (lowest quartile) and population controls.

SF-36 Subscale	Survivor - Perceive Melanoma as Less Serious		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	139	76.8±17.3	507	73.4±18.5	2.8 (-0.5, 6.0)	0.10	0.13
Physical functioning (PF)	141	91.6±14.5	503	87.9±17.3	3.7 (1.0, 6.5)	0.008	0.21
Bodily pain (BP)	141	77.2±20.4	507	73.1±20.9	3.4 (-0.2, 7.1)	0.07	0.15
Physical Role Functioning (RP)	141	91.0±16.6	503	87.6±20.1	3.0 (-0.4, 6.5)	0.09	0.14
Mental Health (MH)	139	79.2±16.1	506	79.1±14.8	0.1 (-2.6, 2.9)	0.92	0.01
Vitality (VT)	139	66.5±17.2	507	65.1±16.8	1.1 (-1.9, 4.2)	0.47	0.06
Emotional Role Functioning (RE)	141	90.8±18.0	503	91.1±17.4	-0.2 (-3.4, 3.0)	0.90	0.01
Social Role Functioning (SF)	141	91.3±16.4	508	89.1±19.2	2.5 (-0.9, 5.9)	0.14	0.12
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.80	
Normal (<7)	113	81.3	410	81.0	1.00		
Borderline/Abnormal (8+)	26	18.7	96	19.0	0.94 (0.56, 1.57)		
HADS Depression – Categories*						0.30	
Normal	129	92.8	462	91.1	1.00		
Borderline/Abnormal (8+)	10	7.2	45	8.9	0.66 (0.30, 1.45)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 21b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors who report melanoma to be very serious (upper 75%) and population controls.

SF-36 Subscale	Survivor - Perceive Melanoma as Very Serious		Population Controls		Fully adjusted*		
	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	429	76.2±17.6	507	73.4±18.5	2.9 (0.7, 5.1)	0.009	0.17
Physical functioning (PF)	430	91.4±14.8	503	87.9±17.3	4.0 (2.2, 5.9)	<0.0001	0.28
Bodily pain (BP)	429	78.6±20.8	507	73.1±20.9	5.4 (2.9, 7.9)	<0.0001	0.28
Physical Role Functioning (RP)	430	90.8±16.8	503	87.6±20.1	3.7 (1.5, 6.0)	0.001	0.22
Mental Health (MH)	429	81.1±14.0	506	79.1±14.8	1.8 (0.0, 3.6)	0.05	0.13
Vitality (VT)	429	67.2±17.0	507	65.1±16.8	2.1 (0.1, 4.2)	0.04	0.13
Emotional Role Functioning (RE)	429	92.6±15.4	503	91.1±17.4	1.9 (-0.2, 3.9)	0.07	0.12
Social Role Functioning (SF)	430	91.8±15.2	508	89.1±19.2	2.7 (0.6, 4.9)	0.01	0.16
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.19	
Normal (<7)	359	84.7	410	81.0	1.00		
Borderline/Abnormal (8+)	65	15.3	96	19.0	0.79 (0.55, 1.13)		
HADS Depression – Categories*						0.03	
Normal	404	94.4	462	91.1	1.00		
Borderline/Abnormal (8+)	24	5.6	45	8.9	0.55 (0.32, 0.96)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 22a. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors who report being less fearful of a second melanoma (below median) and population controls.

	Survivor – Less Fearful of 2 nd Melanoma		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size⁺
General health (GH)	279	78.5±16.8	507	73.4±18.5	4.2 (1.8, 6.7)	0.0009	0.24
Physical functioning (PF)	281	91.6±14.4	503	87.9±17.3	4.0 (1.9, 6.1)	0.0002	0.27
Bodily pain (BP)	281	80.4±19.1	507	73.1±20.9	6.7 (3.9, 9.5)	<0.0001	0.34
Physical Role Functioning (RP)	281	91.8±15.4	503	87.6±20.1	4.6 (2.0, 7.1)	0.0005	0.25
Mental Health (MH)	279	83.6±12.4	506	79.1±14.8	3.8 (1.8, 5.9)	0.0002	0.27
Vitality (VT)	279	69.7±16.2	507	65.1±16.8	3.7 (1.3, 6.0)	0.002	0.22
Emotional Role Functioning (RE)	280	94.2±13.9	503	91.1±17.4	3.3 (1.0, 5.6)	0.005	0.20
Social Role Functioning (SF)	281	93.6±12.9	508	89.1±19.2	3.9 (1.5, 6.4)	0.002	0.23
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.0002	
Normal (<7)	257	92.8	410	81.0	1.00		
Borderline/Abnormal (8+)	20	7.2	96	19.0	0.37 (0.22, 0.62)		
HADS Depression – Categories*						0.002	
Normal	271	97.5	462	91.1	1.00		
Borderline/Abnormal (8+)	7	2.5	45	8.9	0.24 (0.10, 0.58)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

Table 22b. SF-36 subscale scores and HADS Anxiety and Depression categories compared between melanoma survivors who report being more fearful of a second melanoma (above median) and population controls.

	Survivor – More Fearful of 2 nd Melanoma		Population Controls		Fully adjusted*		
SF-36 Subscale	N	Mean±SD	N	Mean±SD	Diff Means (95% CI)	p-value	Effect Size ⁺
General health (GH)	289	74.3±18.0	507	73.4±18.5	1.4 (-1.1, 4.0)	0.27	0.08
Physical functioning (PF)	290	91.7±14.0	503	87.9±17.3	3.9 (1.8, 6.0)	0.0003	0.26
Bodily pain (BP)	289	76.2±21.9	507	73.1±20.9	3.2 (0.4, 6.1)	0.03	0.23
Physical Role Functioning (RP)	290	90.0±17.9	503	87.6±20.1	2.5 (-0.2, 5.1)	0.07	0.13
Mental Health (MH)	289	77.9±15.4	506	79.1±14.8	-1.0 (-3.2, 1.1)	0.36	0.07
Vitality (VT)	289	64.5±17.4	507	65.1±16.8	0.1 (-2.3, 2.5)	0.96	0.00
Emotional Role Functioning (RE)	290	90.5±17.2	503	91.1±17.4	-0.5 (-3.0, 2.0)	0.68	0.03
Social Role Functioning (SF)	290	90.0±17.2	508	89.1±19.2	1.5 (-1.1, 4.1)	0.25	0.08
	N	%	N	%	OR (95% CI)	p-value	
HADS Anxiety – Categories*						0.17	
Normal (<7)	214	75.4	410	81.0	1.00		
Borderline/Abnormal (8+)	70	24.7	96	19.0	1.30 (0.89, 1.88)		
HADS Depression – Categories*						0.68	
Normal	261	90.9	462	91.1	1.00		
Borderline/Abnormal (8+)	26	9.1	45	8.9	0.89 (0.52, 1.53)		

* adjusted for sex, age, education, income, marital status (married/partnered vs. other), BMI category, smoking status and presence of any comorbidities

⁺ Cohen's d; difference in means divided by the standard deviation

8 Part II: Manuscript 3 - A cross-sectional survey of the sun exposure and protection behaviors of long-term melanoma survivors compared to population controls

8.1 Introduction

Melanoma is considered a generally preventable cancer, with excessive UVR exposure being one of the strongest risk factors for the disease.^{16,17} Additional risk factors include a large number of moles and/or freckles, fair skin, family history of melanoma, and immune suppression.¹⁸ Even when diagnosed at an early stage, melanoma can be aggressive and treatment resistant, having the ability to metastasize at the earliest stages.¹⁹ Patients diagnosed with melanoma experience high rates of recurrence, with excess risk of recurrence remaining 20 years after the initial diagnosis^{20,21} and have an approximately 9-fold increased risk of developing another melanoma.²¹

For melanomas that develop as a consequence of UVR exposure, the damage done to the skin prior to the first melanoma cannot be ameliorated and this damage may increase risk of a subsequent melanoma. Importantly, however, UVR exposure following a melanoma diagnosis can be modified to reduce risk of a new melanoma diagnosis.¹⁰¹

It has been suggested that cancer may be a “teachable moment” for health behavior change.¹⁰² Unfortunately, while some cancer survivors initiate positive health behaviors, others do not.¹⁰³ In the case of melanoma, reduction of sun exposure is paramount. Individuals are advised to limit time in the sun during peak hours, seek shade, wear protecting clothing, use sunscreen, and avoid indoor tanning devices.¹⁴

The young age at diagnosis of melanoma for some suggests ample opportunity to engage in improved sun protection behaviors following diagnosis. Surprisingly little research has documented UVR exposure among melanoma survivors. Studies to date on sun protection behaviors among melanoma survivors have been mixed, though most suggest that if an improvement in sun behaviors among melanoma survivors is present, it is moderate.¹⁹⁵ Further clarification of these behaviors in long-term melanoma survivors is needed. In particular, data are lacking on sun exposure patterns and specific sun protection behaviors compared to an appropriately matched control group with measured potential confounders.

The objective of this study was to compare measures of UVR exposure and protection behaviors between melanoma survivors and population controls and explore relationships between these measures and melanoma survivor characteristics.

8.2 Methods

8.2.1 Study Design and Population

See Chapter 6, section 6.1.

8.2.2 Identification of Eligible Participants

See Chapter 6, section 6.2.

8.2.3 Subject recruitment

See Chapter 6, section 6.3.

8.2.4 Data collection and Measures

See Chapter 6, section 6.3 for details on data collection.

The primary outcomes for this study were self-reported sun exposure and protection measures. The questionnaire included nine self-report items related to sun exposure and protection practices developed by leading skin cancer prevention researchers and have been validated.^{169,196} All items had categorical responses. Two questions asked about number of hours outside per day during peak hours (10am-4pm) in the summer separately for weekdays and weekend days using the following categories: 0-30 minutes, 31 minutes-1 hour, 2 hours, 3 hours, 4 hours, 5 hours or 6 hours. Participants were also asked to report the number of red or painful sunburns that lasted a day or more in the past year: 0, 1, 2, 3, 4, or 5 or more. Sun protection methods utilized during the summer on a warm sunny day, including wearing sunscreen, a shirt with sleeves, a hat with a wide brim, staying in the shade, and spending time in the sun in order to get a tan (intentional tanning) were collected using the following categories: Never, Rarely, Sometimes, Often, or Always. The final question asked whether the participant had used a tanning bed or booth in the past 12 months (yes, no). For the purposes of this analysis and ease of interpretation, all of these measures were dichotomized into “optimal” and “suboptimal” categories; the following were considered optimal: weekday sun exposure in the summer of less than two hours, weekend day sun exposure in the summer of less than two hours, no sunburns in the past year, no indoor tanning in the past year, and reporting often or always using sunscreen, often or always wearing a shirt with sleeves, often or always wearing a hat, often or always staying in the shade, and rarely or never intentionally tanning.

Secondary outcomes included three additional items for melanoma survivors only asking whether they avoided sun exposure, wore sun-protective clothing, or used sunscreen more, the same, or less than before their diagnosis or if it was never their habit.¹⁴⁹

Potential confounders, including demographics and comorbidities, were also collected as described in Chapter 7.2.4. In addition, data collected as part of the original Skin Health Study, described elsewhere, were considered.^{100,197} Briefly, data were ascertained using both a self-administered questionnaire and detailed computer-assisted telephone interview. Skin, hair and eye color, presence and pattern of freckles and moles, detailed indoor tanning and residential history, and supplement/medication intake were collected via the self-administered questionnaire. Indoor tanning and sun exposure, history and number of painful sunburns before and after age 18, and sun protection behaviors, including sunscreen use, were collected during the telephone interview. A phenotypic risk score was calculated based on hair and eye color, and tanning ability. The score ranges from 1 for lowest to 5 for highest melanoma risk. For hair color, a score of 1 was assigned for dark brown or black, 2 for blond or light brown, and 3 for red; having eye colors of grey, blue, green or hazel contributed 1 additional point to the phenotype score, as did having no ability to tan.¹⁹⁸

Clinical characteristics of the melanoma diagnosis, including disease stage and location of tumor, when available, were provided by the Minnesota Cancer Surveillance System and supplemented with self-report follow-up survey data as needed.

8.2.5 *Statistical Methods*

For the purposes of this dissertation, 1311 (687 melanoma survivor and 624 control) surveys that were completed and returned by November 1, 2015 were included in the calculations of response rate. At the time of the analysis for this dissertation, data entry was complete for approximately 60% of those who returned paper surveys, resulting in complete data for 592 (86.2%) melanoma survivors and 518 (83.0%) control surveys.

Assessment of Bias

To assess how death and non-response may have biased the results, comparisons were made between those eligible and ineligible for the study and between those who did and did not participate in this follow-up survey using data from the original Skin Health Study as described in Chapter 6.6. Characteristics including sex, age, education, risk factors for melanoma (phenotype, family history of melanoma, sun exposure, sunburns, and sun protection practices), and among melanoma survivors, disease stage and tumor location, were considered.

Identification of Potential Confounding Factors

Demographic, general health characteristics, and pre-diagnosis sun exposure and protection behaviors were compared between melanoma survivors and population controls that completed the survey using Chi-squared tests, t-tests, and Wilcoxon Rank Sum tests as appropriate. To identify potential confounders, each sun exposure and protection outcome was compared across demographic, general health characteristics and risk factors for melanoma separately using Chi-squared tests, t-tests and Wilcoxon Rank Sum tests as appropriate.

Primary Analyses

Primary analyses compared optimal UVR exposure and protection behaviors between melanoma survivors and population controls. Initial comparisons between melanoma survivors and population controls for all categories were conducted using Chi-squared tests. Multivariate logistic regression models, both sex and age-adjusted, and fully-adjusted, were conducted and odds ratios (OR) and 95% confidence intervals (CI) for each outcome are presented. Potential confounders included in the final models were age (continuous), sex, education (high school, vocation/associates, some college, college graduate, graduate/professional degree), income (<\$50,000, \$50,000-\$74,999, \$75,000-\$149,999, \$150,000+, prefer not to say), current smoking status (yes, no), phenotypic risk score (low, intermediate, high), personal history of other skin cancer, family history of melanoma, and sun exposure data reported prior to diagnosis (lifetime sun exposure, outdoor activity sun exposure, mean sunscreen use, and number of sunburns).

To explore whether differences in optimal UVR exposure and sun protection behaviors between melanoma survivors and controls differed according to age or sex, stratified analyses were compared to controls by age group at survey (30-49, 50-59, 60-72) and sex. Analyses were fully adjusted for all confounders, as previously described, and an interaction effect was included to examine whether a statistically significant interaction between melanoma status and age or sex was present. Due to the number of statistical tests performed, p-values related to these primary analyses were adjusted for multiple comparisons using the Benjamini and Hochberg method;¹⁸⁹ adjusted p-values <0.05 were considered statistically significant.

Secondary Analyses

To determine whether particular subgroups of survivors had poorer sun exposure and protection behaviors, analyses of these outcomes among subgroups of melanoma survivors compared to all controls were conducted. Analyses were done separately by melanoma stage (I vs. II/III/IV) and tumor site (head/neck, trunk, lower limb, upper limb). Due to the exploratory nature of these analyses, p-values were not adjusted for multiple comparisons.

Finally, melanoma survivors' report of changes in sun protection behaviors since diagnosis were summarized and compared by sex, age, melanoma stage, and tumor site using Chi-squared and Fisher's Exact tests.

8.3 Results

Population Description and Assessment of Bias

See Chapter 7, Section 7.3.1 for a detailed description of the population and potential for bias due to non-response. Briefly, those who completed the survey were generally similar to those who did not respond, though they were slightly older, more likely to have completed college, and less likely to have ever used indoor tanning.

This analysis included 592 melanoma survivors and 518 control surveys. Among those who completed the survey, melanoma survivors and population controls were not statistically significantly different across most demographic and health characteristics, though melanoma survivors were more likely to have a high phenotypic risk score ($p<0.0001$), more likely to use indoor tanning before their diagnosis ($p=0.003$), and

reported more lifetime sunburns prior to their diagnosis compared to the reference date of the controls ($p < 0.0001$; Table 23).

Identification of Potential Confounding Factors

Age, sex, education, income, smoking status, phenotypic risk score, personal history of population skin cancer and pre-diagnosis measures of sun exposure and protection behaviors were generally associated with the sun exposure and protection measures, though these were not uniform across all behaviors (Tables 24a-24i).

In particular, older individuals were more likely to report greater weekday sun exposure and less sunscreen use compared to younger individuals. Older participants also reported, however, less weekend sun exposure and intentional tanning, fewer sunburns, and were more likely to wear a shirt and hat compared to younger participants. Males were more likely than females to report greater weekday sun exposure, weekend sun exposure and sunburns. Males were also less likely to use sunscreen and stay in the shade compared to females, though they were more likely to wear a shirt and less likely to intentionally tan.

Participants who were more educated reported less weekday sun exposure and intentional tanning and more sunscreen use and wearing of a hat than those who were less educated. Respondents with higher income reported less weekday sun exposure and more sunscreen use, however they also reported greater weekend sun exposure than those with lower income. Participants who were current smokers reported greater weekday sun exposure, more sunburns, less sunscreen use, and were less likely to stay in the shade than those who were not current smokers. Individuals with a low phenotypic risk score

reported more weekday sun exposure, less sunscreen use, were less likely to stay in the shade and were more likely to intentionally tan than those with higher risk scores.

Participants who reported pre-diagnosis indoor tanning, compared to those who did not, reported more sunburns, were more likely to currently tan indoors and intentionally tan outdoors, and were less likely to wear a shirt or hat, though they did also report being more likely to wear sunscreen. Individuals with higher pre-diagnosis sun exposure and outdoor activity exposure were more likely to have greater weekday and weekend sun exposure, more sunburns, and were less likely to use sunscreen and stay in the shade compared to those who reported lower pre-diagnosis sun exposure. These individuals also reported being more likely to wear a shirt and hat and were less likely to intentionally tan than those with lower pre-diagnosis sun exposure. Participants who reported higher pre-diagnosis sunscreen use reported less weekday sun exposure, were less likely to intentionally tan, and reported more sunscreen use, hat use, and staying in the shade than participants with lower pre-diagnosis sunscreen use. Finally, individuals who reported a greater number of lifetime sunburns pre-diagnosis reported more sunburns in the past year, though they were more likely to wear a shirt and hat and less likely to intentionally tan than those with fewer sunburns pre-diagnosis.

Primary Analyses

Detailed survey responses to each sun exposure and protection behavior outcome compared between melanoma survivors and population controls are presented in Table 25. Very few individuals, whether a melanoma survivor or control, reported indoor tanning (n=7 and n=31, respectively). When comparing melanoma survivors with

optimal behavior to that of controls, melanoma survivors were statistically significantly more likely to report optimal behaviors than population controls with the exception of sun exposure on weekend days in the summer (Table 26). Specifically, melanoma survivors, compared to controls, were less likely to spend two or more hours outside on weekdays during the summer (31.1% vs. 43.0%, $p=0.003$), were less likely to report a sunburn in the past year (20.1% vs. 37.0%, $p<0.0001$), were less likely to have indoor tanned in the past year (1.2% vs. 6.1%, $p=0.0004$), were less likely to intentionally tan (10.0% vs. 24.4%, $p<0.0001$). In addition, melanoma survivors were more likely to report often or always engaging in sun protection behaviors, including wearing sunscreen (62.2% vs. 39.7%, $p<0.0001$), a shirt with sleeves (46.7% vs. 65.8%, $p=0.0006$), hat (32.2% vs. 22.9%, $p=0.0004$), and stay in the shade in the summer (48.6% vs. 27.8%, $p<0.0001$). Of note, however, 74.5% of melanoma survivors reported spending two or more hours in the sun on a typical day weekend day in the summer, compared to 78.9% ($p=0.23$) in the control group.

A comparison of optimal UVR exposure and sun protection behaviors between melanoma survivors and controls by age was similar to the overall comparison with the exception of hours spent in the sun on weekend days ($p=0.007$; Table 27a-d). While none of the comparisons within age group were statistically significant, the youngest and oldest melanoma survivors were more likely to avoid sun exposure on weekend days compared to controls whereas those 50-59 years old reported more sun exposure on weekend days compared to controls. While males and females differed in their sun exposure and protection behaviors, whether they were a survivor or not, sex-specific

comparisons between melanoma survivors and controls revealed no differences (Tables 28a-28b).

Secondary Analyses

Secondary analyses exploring the sun exposure and protection behaviors of subgroups of melanoma survivors compared to controls found they did not appear to differ by stage (Tables 29a-29b) or tumor site (Tables 30a-30d).

When looking at self-reported change in key behaviors, most melanoma survivors reported engaging in each behavior more, namely 79.6% reported more effort to avoid exposure to the sun, 62.5% wore more sun-protective clothing, and 78.2% used more sunscreen (Tables 31-33). Sex and age differences were observed. Females were more likely to report than males changing their exposure (85.0% vs. 71.6%, $p=0.001$) and sunscreen behaviors (84.5% vs. 68.9%, $p<0.0001$) and males were more likely to use and change their use of protective clothing compared to females (64.6% vs. 61.0%, $p=0.004$). Younger individuals were more likely to use sunscreen ($p<0.0001$) and less likely to use protective clothing ($p=0.02$). Finally, those with tumors on their head or neck were less likely to change their sun exposure habits compared to other tumor sites ($p=0.02$). No other statistically significant differences in self-reported changes in behaviors by melanoma stage or tumor site were observed.

8.4 Discussion

This population-based cross-sectional study is the largest to date to report UVR exposure and protection behaviors of long-term melanoma survivors compared with an appropriate population control group. Exposure to UVR is a significant and modifiable

risk factor for melanoma, with intermittent exposure and sunburns identified as the main culprits.¹⁹⁹ Like all cancer survivors, melanoma survivors are at risk for subsequent cancer,²⁰⁰ however, UVR exposure following a melanoma diagnosis can be modified to reduce risk of a new melanoma diagnosis.¹⁰¹ Consistent with other health behaviors reported by cancer survivors²⁰¹ and a recent meta-analysis of the limited available literature among melanoma survivors,¹⁹⁵ our study indicates long-term melanoma survivors report healthier UVR exposure and protection behaviors compared to population controls and self-report changes since diagnosis. Despite this, opportunities remain to reduce future melanoma risk among melanoma survivors as a significant proportion still report elevated sun exposure, sunburns and suboptimal sun protection behaviors.

8.4.1 Ultraviolet Radiation Exposure

While debate continues about the best sun protection methods for skin cancer prevention,²⁰² UVR avoidance, including from sun and artificial sources, is crucial. Few studies report UVR exposure among melanoma survivors, with most focusing on frequency of sunbathing or indoor tanning as opposed to time spent in the sun. Consistent with our results, a recent qualitative study reported many melanoma survivors are more conscious of sun exposure and protection.⁸³ Surprisingly, however, melanoma survivors in our study reported being outside two or more hours on weekend days during peak hours in the summer at similar rates as controls. This is concerning because it implies a sun exposure pattern that is intermittent in nature, which has been associated with increased melanoma risk.²⁰³ Our finding may be due, in part, to the long period of

time since melanoma diagnosis. A small prospective study of melanoma survivors and controls (N=40) found that UVR exposure was initially lower among survivors compared to controls but then converged over the three-year study.^{108,109}

We found that few melanoma survivors and controls reported indoor tanning in the past year. This may be explained by the fact that this population is likely aging out of this habit and awareness of the negative effects of indoor tanning has been increasing. While long-term melanoma survivors were less likely to report indoor tanning in the past year than controls, a small number of survivors reported still engaging in this behavior. This phenomenon has been reported elsewhere^{107,138} and indicates a small proportion of individuals will continue this high-risk behavior despite a melanoma diagnosis.

8.4.2 *Sunburns*

Sunburn is a critical measure of excessive sun exposure. A meta-analysis found increased risk of melanoma with increasing sunburns throughout the lifetime, not just childhood,²⁰⁴ emphasizing the importance of continued and improved sunburn prevention among melanoma survivors. Few studies have reported sunburn occurrence among melanoma survivors, however. A large international online survey had a subgroup of participants who reported a previous melanoma diagnosis and 27% of them reported at least one severe sunburn in the past year,¹⁰⁶ similar our result of 20%. While our study indicates melanoma survivors are about half as likely to report a sunburn as population controls, a significant minority engage in behaviors that result in sunburns.

Studies of the general United States population have reported that the percent of females with sunburns in the past year is lower than that of than males¹¹⁷ and the percent

of adults with sunburns in past year decreases with age.²⁰⁵ Our results were similar and suggest that while differences were found among melanoma survivors by age and sex, they follow the sunburn trends of the general population.

8.4.3 *Sunscreen*

The use of sunscreen as a form of UVR protection has been debated, though the general conclusion is that broad-spectrum sunscreen is a part of skin cancer prevention.²⁰⁶ Other methods of sun protection are encouraged first, including wearing protective clothing and staying in the shade. This is due, in part, to research showing that individuals who apply sunscreen stay in the sun longer.²⁰⁷ In addition, numerous barriers to proper sunscreen use have been reported, including difficulty of use if engaging in physical activity, planning to be in the sun for only a short period of time, or the time needed to apply prior to exposure.²⁰⁸ A randomized controlled trial in Australia, however, found participants randomized to daily sunscreen use had fewer new primary melanomas ten years later compared to those assigned to discretionary sunscreen.²⁰⁹

A number of studies have reported sunscreen use among melanoma survivors alone,^{110,111,114,116,138,210,211} however, a review found that general population estimates of regular sunscreen use vary greatly in the literature (7-90%),⁷³ therefore it is critical to simultaneously collect data on population controls for comparison. Few studies have included a control group^{104,107-109}; the largest to date compared 156 melanoma survivors to 11408 respondents without cancer who participated in 2005 and 2007 National Cancer Institute Health Information National Trends Surveys (HINTS).¹⁰⁷ The results were similar to our study, though HINTS respondents reported slightly lower frequencies of

sunscreen use with 51% of melanoma survivors and 35% of cancer-free controls reporting sunscreen use in the past year. Our study also found that females and younger individuals, regardless of melanoma diagnosis status, were more likely to use sunscreen, which has been previously reported in the general population²¹² and among melanoma survivors.¹¹⁶

8.4.4 Other Ultraviolet Radiation Protection Behaviors

Wearing UVR protective clothing and staying in the shade during peak hours are recommended as important components of proper sun protection. A few studies have reported increases in sun-protection behaviors among melanoma patients following diagnosis.¹¹⁰⁻¹¹² Studies of melanoma survivors alone, one of which included longer-term survivors, found modest sun protection behaviors similar to our results.^{114,116} In comparison to non-cancer controls, two studies found that melanoma survivors use sunscreen and seek shade more frequently than controls,^{107,108} whereas another study found sun protection behaviors were comparable but not greater than general population estimates.¹¹⁴ Our study is the largest to date and after adjustment for potential confounding factors, found melanoma survivors are more likely to report optimal sun protection behaviors. As found previously, these differences were modest, however, with more than half reporting they do not wear a hat or stay in the shade during peak hours.

The differences in these behaviors observed by sex in our study have been previously reported among melanoma survivors, with males being more likely to wear protective clothing and females being more likely to stay in the shade.^{114,116,117} These differences have also been reported in the United States general population,¹¹⁵ suggesting

any observed differences reflect the habits of the general population rather than being specific to a melanoma diagnosis.

8.4.5 Limitations

Our study provides a more complete picture of the UVR exposure and protection habits of melanoma survivors as compared to a similarly recruited population control group than previous research. While this study has many strengths, including the large sample size, population-based sample, and inclusion of a control group with measured confounding factors, we note important limitations. As with other self-reported measures, participants may have over-reported behaviors due to social desirability, particularly among melanoma survivors, resulting in an overestimate of sun protection behaviors leading to potential bias. The self-report measures used have been previously shown to compare well with direct observation measures, however,¹⁹⁶ and the anonymity of the questionnaire makes this less likely.

Another limitation is that survivors who responded to our survey may be more likely to practice health behaviors, or those who are still alive may be those who frequently use optimal sun protection behaviors.

Finally, while melanoma is most prevalent among non-Hispanic whites, these data do not allow for an examination of possible differences in effects by race/ethnicity due to the fairly homogenous population in Minnesota. It is noteworthy, however, that the proportion of respondents reporting sunburn in the past year among the controls is similar to those reported in national United States survey studies.^{115,205}

8.4.6 *Conclusion*

Despite limitations, this study contributes to the field as the largest to date to examine the UVR exposure and protection behaviors of long-term melanoma survivors as compared to similarly recruited controls. While a melanoma diagnosis appears to serve as a trigger for behavior change for many, resulting in better sun protection behaviors among survivors compared to controls, one-fifth of survivors experienced sunburn in the past year and many reported engaging in suboptimal sun protection behaviors. Barriers to sun protection in the general population have been identified as “inconvenience, forgetting to use sun safety measures, desire to be tanned, and protective clothing being too hot to wear.”¹¹³ Additional research is needed to determine barriers to sun protection in melanoma survivors in order to guide development of interventions to further improve sun behaviors and reduce risk of skin cancer in the future.

Table 23. Demographic and general health characteristics among melanoma survivors and population controls that completed the follow-up survey.

	Melanoma Survivors N=592		Population Controls N=518		
Variable	N	%	N	%	p-value
Phenotypic Risk Index					<0.0001
Low	159	27.1	194	37.5	
Intermediate	252	42.9	227	43.8	
High	176	30.0	97	18.7	
Personal History of Non-Melanoma Skin Cancer					0.93
No	549	95.0	480	94.9	
Yes	29	5.0	26	5.1	
Family history of melanoma					0.99
No	406	68.6	355	68.5	
Yes	186	31.4	163	31.5	
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					0.003
No	235	39.7	251	48.5	
Yes	357	60.3	267	51.5	
Sun Exposure – Before Diagnosis, mean±SD	591	2542±1667	518	2660±1659	0.15
Outdoor Activity Exposure – Before Diagnosis, mean±SD	591	2004±1653	518	2054±1664	0.47
Mean sunscreen use –Before Diagnosis, mean±SD	592	1.37±1.00	518	1.31±1.02	0.24
Lifetime sunburns – Before Diagnosis, median (min, max)	590	10 (0-400)	516	6 (0-250)	<0.0001

Table 24a. Associations between demographic and previous sun characteristics by hours of weekday sun exposure in the summer.

	Weekday Sun 1 hour or less		Weekday Sun 2 hours or more		
Variable	N	%	N	%	p-value
Age at survey					<0.0001
30-39	63	9.1	18	4.5	
40-49	123	17.8	56	13.9	
50-59	273	39.4	131	32.5	
60-72	234	33.8	198	49.1	
Sex					<0.0001
Male	232	34.3	190	48.8	
Female	444	65.7	199	51.2	
Race					0.56
White, Non-Hispanic	681	98.3	394	97.8	
Other	12	1.7	9	2.2	
Education					<0.0001
High school	51	7.5	68	17.4	
Vocational/Associates	125	18.5	76	19.4	
Some college	100	14.8	71	18.2	
College graduate	232	34.3	99	25.3	
Graduate/professional degree	169	25.0	77	19.7	
Marital Status					0.85
Never married	35	5.2	19	4.9	
Married/Partnered	565	83.6	327	83.4	
Widowed	12	1.8	10	2.6	
Divorced	64	9.5	36	9.2	
Income					<0.0001
<\$50,000	68	10.1	65	16.6	
\$50,000-74,999	103	15.3	84	21.5	
\$75,000-\$149,999	294	43.6	144	36.8	
\$150,000+	149	22.1	56	14.3	
Prefer not to say	61	9.0	42	10.7	
Body Mass Index (BMI)					0.25
Underweight (<18.5 kg/m ²)	1	0.1	4	1.0	
Normal (18.5-24.9 kg/m ²)	268	38.7	153	38.0	
Overweight (25.0-29.9 kg/m ²)	241	34.8	137	34.0	
Obese (30.0+ kg/m ²)	183	26.4	109	27.1	
Current Smoker					0.02
No	656	94.8	365	91.0	
Yes	36	5.2	36	9.0	
Phenotypic Risk Index					0.004
Low	199	28.9	149	37.1	
Intermediate	301	43.7	172	42.8	
High	189	27.4	81	20.2	
Personal History of Non-Melanoma Skin Cancer					0.84
No	647	95.0	377	94.7	
Yes	34	5.0	21	5.3	
Family history of melanoma					0.65
No	469	67.7	278	69.0	
Yes	224	32.3	125	31.0	

	Weekday Sun 1 hour or less		Weekday Sun 2 hours or more		
	N	%	N	%	p-value
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					0.26
No	294	42.4	185	45.9	
Yes	399	57.6	218	54.1	
Sun Exposure – Before Diagnosis, mean±SD	692	2113±1156	403	3411±2010	<0.0001
Outdoor Activity Exposure – Before Diagnosis, mean±SD	693	1727±1346	402	2545±1978	<0.0001
Mean sunscreen use –Before Diagnosis, mean±SD	693	1.45±1.02	403	1.16±0.96	<0.0001
Lifetime sunburns – Before Diagnosis, median (min, max)	691	7 (0, 400)	401	9 (0, 250)	0.22

Table 24b. Associations between demographic and previous sun characteristics by hours of weekday sun exposure in the summer.

	Weekend Sun 1 hour or less		Weekend Sun 2 hours or more		
Variable	N	%	N	%	p-value
Age at survey					0.02
30-39	15	5.8	66	7.9	
40-49	31	12.1	148	17.7	
50-59	90	35.0	314	37.5	
60-72	121	47.1	310	37.0	
Sex					<0.0001
Male	67	26.9	355	43.6	
Female	182	73.1	460	56.4	
Race					0.80
White, Non-Hispanic	4	1.6	17	2.0	
Other	253	98.4	821	98.0	
Education					0.42
High school	22	8.8	97	11.9	
Vocational/Associates	44	17.7	157	19.2	
Some college	37	14.9	134	16.4	
College graduate	80	32.1	250	30.6	
Graduate/professional degree	66	26.5	180	22.0	
Marital Status					0.68
Never married	16	6.4	38	4.7	
Married/Partnered	204	81.9	687	84.0	
Widowed	6	2.4	16	2.0	
Divorced	23	9.2	77	9.4	
Income					0.03
<\$50,000	41	16.5	92	11.3	
\$50,000-74,999	44	17.7	143	17.5	
\$75,000-\$149,999	88	35.5	349	42.7	
\$150,000+	43	17.3	162	19.8	
Prefer not to say	32	12.9	71	8.7	
Body Mass Index (BMI)					0.61
Underweight (<18.5 kg/m ²)	1	0.4	4	0.5	
Normal (18.5-24.9 kg/m ²)	90	35.0	331	39.5	
Overweight (25.0-29.9 kg/m ²)	95	37.0	282	33.7	
Obese (30.0+ kg/m ²)	71	27.6	221	26.4	
Current Smoker					0.26
No	243	94.9	777	92.9	
Yes	13	5.1	59	7.1	
Phenotypic Risk Index					0.07
Low	75	29.5	273	32.7	
Intermediate	102	40.2	370	44.3	
High	77	30.3	193	23.1	
Personal History of Non-Melanoma Skin Cancer					0.46
No	235	94.0	788	95.2	
Yes	15	6.0	40	4.8	
Family history of melanoma					0.17
No	184	71.6	562	67.1	
Yes	73	28.4	276	32.9	

	Weekend Sun 1 hour or less		Weekend Sun 2 hours or more		
	N	%	N	%	p-value
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					0.22
No	121	47.1	358	42.7	
Yes	136	52.9	480	57.3	
Sun Exposure – Before Diagnosis, mean±SD	257	2082±1160	837	2748±1744	<0.0001
Outdoor Activity Exposure – Before Diagnosis, mean±SD	257	1756±1532	837	2110±1683	0.0002
Mean sunscreen use –Before Diagnosis, mean±SD	257	1.35±1.01	838	1.34±1.01	0.85
Lifetime sunburns – Before Diagnosis, median (min, max)	257	8 (0, 115)	834	8 (0, 400)	0.85

Table 24c. Associations between demographic and previous sun characteristics by sunburns in past year.

Variable	No sunburns in past year		1 or more sunburns in past year		p-value
	N	%	N	%	
Age at survey					<0.0001
30-39	42	5.3	39	12.7	
40-49	99	12.5	80	26.1	
50-59	296	37.4	109	35.5	
60-72	355	44.8	79	25.7	
Sex					0.05
Male	291	37.9	133	44.3	
Female	477	62.1	167	55.7	
Race					0.58
White, Non-Hispanic	778	98.2	300	97.7	
Other	14	1.8	7	2.3	
Education					0.17
High school	90	11.7	30	10.0	
Vocational/Associates	131	17.0	70	23.3	
Some college	122	15.8	49	16.3	
College graduate	247	32.0	85	28.3	
Graduate/professional degree	181	23.5	66	22.0	
Marital Status					0.46
Never married	34	4.4	20	6.6	
Married/Partnered	645	83.8	249	82.7	
Widowed	17	2.2	5	1.7	
Divorced	74	9.6	27	9.0	
Income					0.73
<\$50,000	97	12.6	38	12.6	
\$50,000-74,999	133	17.3	54	17.9	
\$75,000-\$149,999	313	40.8	125	41.5	
\$150,000+	145	18.9	61	20.3	
Prefer not to say	80	10.4	23	7.6	
Body Mass Index (BMI)					0.31
Underweight (<18.5 kg/m ²)	5	0.6	0	0.0	
Normal (18.5-24.9 kg/m ²)	312	39.4	109	35.5	
Overweight (25.0-29.9 kg/m ²)	268	33.8	112	36.5	
Obese (30.0+ kg/m ²)	207	26.1	86	28.0	
Current Smoker					0.007
No	748	94.7	276	90.2	
Yes	42	5.3	30	9.8	
Phenotypic Risk Index					0.65
Low	254	32.2	95	31.2	
Intermediate	336	42.6	139	45.6	
High	199	25.2	71	23.3	
Personal History of Non-Melanoma Skin Cancer					0.29
No	735	94.5	292	96.1	
Yes	43	5.5	12	4.0	
Family history of melanoma					0.13
No	551	69.6	199	64.8	
Yes	241	30.4	108	35.2	

	No sunburns in past year		1 or more sunburns in past year		
	N	%	N	%	p- value
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					0.01
No	364	46.0	116	37.8	
Yes	428	54.0	191	62.2	
Sun Exposure – Before Diagnosis, mean±SD	791	2599±1611	307	2608±1805	0.37
Outdoor Activity Exposure – Before Diagnosis, mean±SD	792	2100±1696	306	1860±1553	0.01
Mean sunscreen use –Before Diagnosis, mean±SD	792	1.37±1.04	307	1.27±0.92	0.25
Lifetime sunburns – Before Diagnosis, median (min, max)	791	7 (0, 350)	304	10 (0, 400)	0.0006

Table 24d. Associations between demographic and previous sun characteristics by report of indoor tanning in past year.

	No indoor tanning		Indoor tanning		
Variable	N	%	N	%	p-value
Age at survey					0.05
30-39	76	7.2	5	13.2	
40-49	168	15.8	11	29.0	
50-59	394	37.1	12	31.6	
60-72	423	39.9	10	26.3	
Sex					0.02
Male	416	40.4	8	21.1	
Female	615	59.7	30	79.0	
Race					0.53
White, Non-Hispanic	1041	98.1	37	97.4	
Other	20	1.9	1	2.6	
Education					0.61
High school	114	11.0	6	15.8	
Vocational/Associates	194	18.8	8	21.1	
Some college	162	15.7	8	21.1	
College graduate	322	31.1	10	26.3	
Graduate/professional degree	242	23.4	6	15.8	
Marital Status					0.22
Never married	52	5.0	2	5.3	
Married/Partnered	866	83.8	29	76.3	
Widowed	22	2.1	0	0.0	
Divorced	94	9.1	7	18.4	
Income					0.84
<\$50,000	132	12.8	4	10.5	
\$50,000-74,999	178	17.3	9	23.7	
\$75,000-\$149,999	421	40.8	16	42.1	
\$150,000+	201	19.5	6	15.8	
Prefer not to say	100	9.7	3	7.9	
Body Mass Index (BMI)					0.73
Underweight (<18.5 kg/m ²)	5	0.5	0	0.0	
Normal (18.5-24.9 kg/m ²)	409	38.6	14	36.8	
Overweight (25.0-29.9 kg/m ²)	364	34.3	16	42.1	
Obese (30.0+ kg/m ²)	283	26.7	8	21.1	
Current Smoker					0.51
No	988	93.3	37	97.4	
Yes	71	6.7	1	2.6	
Phenotypic Risk Index					0.95
Low	336	31.8	13	34.2	
Intermediate	459	43.5	16	42.1	
High	261	24.7	9	23.7	
Personal History of Non-Melanoma Skin Cancer					0.72
No	991	94.8	37	97.4	
Yes	54	5.2	1	2.6	
Family history of melanoma					0.49
No	726	68.4	24	63.2	
Yes	335	31.6	14	36.8	

	No indoor tanning		Indoor tanning		
	N	%	N	%	p-value
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					<0.0001
No	479	45.2	2	5.3	
Yes	582	54.9	36	94.7	
Sun Exposure – Before Diagnosis, mean±SD	1060	2604±1671	38	2483±1438	0.63
Outdoor Activity Exposure – Before Diagnosis, mean±SD	1060	2028±1665	38	2265±1518	0.20
Mean sunscreen use –Before Diagnosis, mean±SD	1061	1.35±1.02	38	1.05±0.72	0.11
Lifetime sunburns – Before Diagnosis, median (min, max)	1058	8 (0, 400)	37	5 (0, 80)	0.20

Table 24e. Associations between demographic and previous sun characteristics by current sunscreen use.

	Often/Always Use Sunscreen		Never/Rarely/Sometimes Use Sunscreen		
Variable	N	%	N	%	p-value
Age at survey					<0.0001
30-39	51	9.0	30	5.7	
40-49	110	19.3	69	13.0	
50-59	226	39.7	180	34.0	
60-72	182	32.0	251	47.4	
Sex					<0.0001
Male	161	29.0	263	51.2	
Female	394	71.0	251	48.8	
Race					0.03
White, Non-Hispanic	563	99.0	515	97.2	
Other	6	1.1	15	2.8	
Education					<0.0001
High school	38	6.8	82	15.9	
Vocational/Associates	90	16.2	112	21.7	
Some college	80	14.4	90	17.4	
College graduate	197	35.4	135	26.2	
Graduate/professional degree	151	27.2	97	18.8	
Marital Status					0.23
Never married	25	4.5	29	5.6	
Married/Partnered	472	54.9	423	82.0	
Widowed	14	2.5	8	1.6	
Divorced	45	8.1	56	10.9	
Income					<0.0001
<\$50,000	49	8.8	87	16.9	
\$50,000-74,999	86	15.5	101	19.6	
\$75,000-\$149,999	234	42.2	203	39.3	
\$150,000+	137	24.7	70	3.6	
Prefer not to say	48	8.7	55	10.7	
Body Mass Index (BMI)					0.0003
Underweight (<18.5 kg/m ²)	2	0.4	3	0.6	
Normal (18.5-24.9 kg/m ²)	253	44.5	170	32.1	
Overweight (25.0-29.9 kg/m ²)	183	32.2	197	37.2	
Obese (30.0+ kg/m ²)	131	23.0	160	30.2	
Current Smoker					0.0005
No	545	96.0	480	90.7	
Yes	23	4.1	49	9.3	
Phenotypic Risk Index					<0.0001
Low	144	25.4	205	38.9	
Intermediate	253	44.6	222	42.1	
High	170	30.0	100	19.0	
Personal History of Non-Melanoma Skin Cancer					0.12
No	526	93.9	502	96.0	
Yes	34	6.1	21	4.0	

	Often/Always Use Sunscreen		Never/Rarely/Sometimes Use Sunscreen		
	N	%	N	%	p-value
Family history of melanoma					0.63
No	392	68.9	358	67.6	
Yes	177	31.1	172	32.5	
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					<0.0001
No	212	37.3	269	50.8	
Yes	357	62.7	261	49.3	
Sun Exposure – Before Diagnosis, mean±SD	569	2211±1279	529	3018±1910	<0.0001
Outdoor Activity Exposure – Before Diagnosis, mean±SD	569	1803±1388	529	2287±1880	<0.0001
Mean sunscreen use –Before Diagnosis, mean±SD	569	1.74±1.01	530	0.92±0.83	<0.0001
Lifetime sunburns – Before Diagnosis, median (min, max)	568	8 (0, 400)	527	8 (0, 350)	0.26

Table 24f. Associations between demographic and previous sun characteristics by use of shirt with sleeves.

Variable	Often/Always Wear Shirt w/ Sleeves		Never/Rarely/Sometimes Wear Shirt w/ Sleeves		p-value
	N	%	N	%	
Age at survey					<0.0001
30-39	38	4.8	43	13.8	
40-49	110	14.0	69	22.2	
50-59	287	36.6	117	37.6	
60-72	350	44.6	82	26.4	
Sex					<0.0001
Male	376	49.0	48	16.1	
Female	391	51.0	251	84.0	
Race					0.98
White, Non-Hispanic	770	98.1	305	98.1	
Other	15	1.9	6	1.9	
Education					0.18
High school	78	10.1	41	13.7	
Vocational/Associates	151	19.6	51	17.0	
Some college	113	14.7	56	18.7	
College graduate	243	31.6	88	29.3	
Graduate/professional degree	184	23.9	64	21.3	
Marital Status					0.69
Never married	38	4.9	15	5.0	
Married/Partnered	646	84.0	247	82.3	
Widowed	17	2.2	5	1.7	
Divorced	68	8.8	33	11.0	
Income					0.54
<\$50,000	95	12.4	41	13.7	
\$50,000-74,999	138	18.0	49	16.4	
\$75,000-\$149,999	304	39.6	131	43.8	
\$150,000+	157	20.4	50	16.7	
Prefer not to say	74	9.6	28	9.4	
Body Mass Index (BMI)					<0.0001
Underweight (<18.5 kg/m ²)	3	0.4	2	0.6	
Normal (18.5-24.9 kg/m ²)	267	34.0	153	49.2	
Overweight (25.0-29.9 kg/m ²)	291	37.1	89	28.6	
Obese (30.0+ kg/m ²)	224	28.5	67	21.5	
Current Smoker					0.13
No	737	94.1	285	91.6	
Yes	46	5.9	26	8.4	
Phenotypic Risk Index					0.49
Low	252	32.3	96	30.9	
Intermediate	331	42.4	144	46.3	
High	197	25.3	71	22.8	
Personal History of Non-Melanoma Skin Cancer					0.11
No	732	94.3	294	96.7	
Yes	44	5.7	10	3.3	

	Often/Always Wear Shirt w/ Sleeves		Never/Rarely/Sometimes Wear Shirt w/ Sleeves		p-value
	N	%	N	%	
Family history of melanoma					0.14
No	546	69.6	202	65.0	
Yes	239	30.5	109	35.1	
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					<0.0001
No	397	50.6	83	26.7	
Yes	388	49.4	228	73.3	
Sun Exposure – Before Diagnosis, mean±SD	784	2707±1703	311	2336±1533	<0.0001
Outdoor Activity Exposure – Before Diagnosis, mean±SD	784	2048±1637	311	2008±1725	0.37
Mean sunscreen use – Before Diagnosis, mean±SD	785	1.38±1.04	311	1.25±0.93	0.16
Lifetime sunburns – Before Diagnosis, median (min, max)	783	8 (0, 250)	309	7 (0, 400)	0.01

Table 24g. Associations between demographic and previous sun characteristics by use of hat.

	Often/Always Wear Hat		Never/Rarely/ Sometimes Wear Hat		
Variable	N	%	N	%	p-value
Age at survey					<0.0001
30-39	9	2.9	72	9.1	
40-49	33	10.8	146	18.5	
50-59	116	37.9	289	36.6	
60-72	148	48.4	282	35.7	
Sex					<0.0001
Male	160	53.5	263	34.3	
Female	139	46.5	503	65.7	
Race					0.67
White, Non-Hispanic	301	98.4	773	98.0	
Other	5	1.6	16	2.0	
Education					0.001
High school	24	8.0	93	12.1	
Vocational/Associates	44	14.7	157	20.4	
Some college	42	14.1	128	16.6	
College graduate	97	32.4	235	30.6	
Graduate/professional degree	92	30.8	156	20.3	
Marital Status					0.42
Never married	10	3.3	44	5.7	
Married/Partnered	255	85.3	636	82.7	
Widowed	7	2.3	15	2.0	
Divorced	27	9.0	74	9.6	
Income					0.29
<\$50,000	28	9.4	106	13.8	
\$50,000-74,999	50	16.8	137	17.8	
\$75,000-\$149,999	124	41.6	312	40.6	
\$150,000+	64	21.5	143	18.6	
Prefer not to say	32	10.7	70	9.1	
Body Mass Index (BMI)					0.23
Underweight (<18.5 kg/m ²)	1	0.3	4	0.5	
Normal (18.5-24.9 kg/m ²)	117	38.2	305	38.7	
Overweight (25.0-29.9 kg/m ²)	118	38.6	260	33.0	
Obese (30.0+ kg/m ²)	70	22.9	220	27.9	
Current Smoker					0.44
No	288	94.4	734	93.2	
Yes	17	5.6	54	6.9	
Phenotypic Risk Index					0.15
Low	90	29.6	257	32.7	
Intermediate	127	41.8	348	44.3	
High	87	28.6	181	23.0	
Personal History of Non-Melanoma Skin Cancer					0.42
No	284	94.0	740	95.2	
Yes	18	6.0	37	4.8	

	Often/Always Wear Hat		Never/Rarely/Sometimes Wear Hat		
	N	%	N	%	p-value
Family history of melanoma					0.38
No	203	66.3	545	69.1	
Yes	103	33.7	244	30.9	
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					<0.0001
No	182	59.5	296	37.5	
Yes	124	40.5	493	62.5	
Sun Exposure – Before Diagnosis, mean±SD	305	2838±1619	789	2506±1671	<0.0001
Outdoor Activity Exposure – Before Diagnosis, mean±SD	306	2242±1650	789	1957±1661	0.0003
Mean sunscreen use –Before Diagnosis, mean±SD	306	1.48±1.05	789	1.29±0.99	0.01
Lifetime sunburns – Before Diagnosis, median (min, max)	306	9 (0, 250)	785	7 (0, 400)	0.02

Table 24h. Associations between demographic and previous sun characteristics by staying in the shade.

	Often/Always Stay in the Shade		Never/Rarely/Sometimes Stay in the Shade		
Variable	N	%	N	%	p-value
Age at survey					0.18
30-39	27	6.3	54	8.1	
40-49	59	13.9	120	17.9	
50-59	164	38.5	241	36.0	
60-72	176	41.3	254	38.0	
Sex					0.0009
Male	139	33.5	284	43.7	
Female	276	66.5	366	56.3	
Race					0.60
White, Non-Hispanic	419	98.4	655	97.9	
Other	7	1.6	14	2.1	
Education					0.29
High school	48	11.5	70	10.7	
Vocational/Associates	72	17.3	129	19.8	
Some college	57	13.7	112	17.2	
College graduate	142	34.1	190	29.1	
Graduate/professional degree	97	23.3	151	23.2	
Marital Status					0.43
Never married	23	5.5	31	4.8	
Married/Partnered	344	52.7	548	84.1	
Widowed	12	2.9	10	1.5	
Divorced	37	8.9	63	9.7	
Income					0.57
<\$50,000	56	13.6	79	12.1	
\$50,000-74,999	71	17.2	115	17.6	
\$75,000-\$149,999	176	42.6	260	39.8	
\$150,000+	77	18.6	130	19.9	
Prefer not to say	33	8.0	69	10.6	
Body Mass Index (BMI)					0.54
Underweight (<18.5 kg/m ²)	1	0.2	4	0.6	
Normal (18.5-24.9 kg/m ²)	157	36.9	265	39.6	
Overweight (25.0-29.9 kg/m ²)	147	34.5	230	34.4	
Obese (30.0+ kg/m ²)	121	28.4	170	25.4	
Current Smoker					0.03
No	405	95.5	617	92.2	
Yes	19	4.5	52	7.8	
Phenotypic Risk Index					0.0002
Low	113	26.8	234	35.0	
Intermediate	178	42.2	297	44.5	
High	131	31.0	137	20.5	
Personal History of Non-Melanoma Skin Cancer					0.002
No	385	92.3	639	96.5	
Yes	32	7.7	23	3.5	

	Often/Always Stay in the Shade		Never/Rarely/Sometimes Stay in the Shade		
	N	%	N	%	p-value
Family history of melanoma					0.35
No	298	7.0	450	67.3	
Yes	128	30.1	219	32.7	
MEASURES FROM ORIGINAL STUDY					
Indoor tanning use prior to diagnosis/reference					0.90
No	187	43.9	291	43.5	
Yes	239	56.1	378	56.5	
Sun Exposure – Before Diagnosis, mean±SD	425	2304±1335	669	2787±1817	0.0004
Outdoor Activity Exposure – Before Diagnosis, mean±SD	426	1898±1443	668	2125±1783	0.09
Mean sunscreen use –Before Diagnosis, mean±SD	426	1.48±1.00	669	1.25±1.00	<0.0001
Lifetime sunburns – Before Diagnosis, median (min, max)	425	7 (0, 350)	666	8 (0, 400)	0.92

Table 24i. Associations between demographic and previous sun characteristics by whether they intentionally tan.

Variable	Rarely/Never Intentionally Tan		Sometimes/Often/Always Intentionally Tan		p-value
	N	%	N	%	
Age at survey					<0.0001
30-39	56	6.1	25	13.7	
40-49	132	14.4	47	25.7	
50-59	343	37.5	62	33.9	
60-72	382	41.9	49	26.8	
Sex					<0.0001
Male	379	42.6	45	25.4	
Female	511	57.4	132	74.6	
Race					0.77
White, Non-Hispanic	896	98.0	180	98.4	
Other	18	2.0	3	1.6	
Education					0.006
High school	97	10.9	22	12.4	
Vocational/Associates	160	17.9	42	23.7	
Some college	130	14.6	39	22.0	
College graduate	288	32.3	44	24.9	
Graduate/professional degree	218	24.4	30	17.0	
Marital Status					0.36
Never married	42	4.7	12	6.8	
Married/Partnered	751	84.1	143	80.8	
Widowed	20	2.2	2	1.1	
Divorced	80	9.0	20	11.3	
Income					0.37
<\$50,000	113	12.7	23	13.0	
\$50,000-74,999	151	17.0	35	19.8	
\$75,000-\$149,999	372	41.8	65	36.7	
\$150,000+	166	18.6	41	23.2	
Prefer not to say	89	10.0	13	7.3	
Body Mass Index (BMI)					0.24
Underweight (<18.5 kg/m ²)	4	0.4	1	0.55	
Normal (18.5-24.9 kg/m ²)	341	37.3	81	44.3	
Overweight (25.0-29.9 kg/m ²)	317	34.7	62	33.9	
Obese (30.0+ kg/m ²)	252	27.6	39	21.3	
Current Smoker					0.19
No	856	93.9	167	91.3	
Yes	56	6.1	16	8.7	
Phenotypic Risk Index					0.03
Low	286	31.4	62	34.1	
Intermediate	386	42.4	89	48.9	
High	238	26.2	31	17.0	
Personal History of Non-Melanoma Skin Cancer					0.42
No	853	94.7	173	96.1	
Yes	48	5.3	7	3.9	

	Rarely/Never Intentionally Tan		Sometimes/Often/Always Intentionally Tan		
	N	%	N	%	p-value
Family history of melanoma					0.58
No	620	67.8	128	70.0	
Yes	294	32.2	55	30.1	
<i>MEASURES FROM ORIGINAL STUDY</i>					
Indoor tanning use prior to diagnosis/reference					<0.0001
No	441	48.3	38	20.8	
Yes	473	51.8	145	79.2	
Sun Exposure – Before Diagnosis, mean±SD	913	2626±1644	183	2486±1753	0.04
Outdoor Activity Exposure – Before Diagnosis, mean±SD	913	2040±1657	183	2022±1688	0.49
Mean sunscreen use –Before Diagnosis, mean±SD	914	1.38±1.02	183	1.18±0.90	0.03
Lifetime sunburns – Before Diagnosis, median (min, max)	912	8 (0, 350)	181	6 (0, 400)	0.02

Table 25. Sun exposure and protection habits by melanoma survivors and population controls.

	Melanoma Survivors		Population Controls		
	N	%	N	%	p-value
Hours outside in summer on Weekdays					0.0009
0-30 minutes	200	34.0	145	28.6	
31 minutes to 1 hour	204	34.6	144	28.4	
2 hours	100	17.0	94	18.5	
3 hours	33	5.6	53	10.5	
4 hours	23	3.9	40	7.9	
5 hours	13	2.2	12	2.4	
6 hours	16	2.7	19	3.8	
Hours outside in summer on Weekend days					0.11
0-30 minutes	49	8.3	27	5.3	
31 minutes to 1 hour	101	17.2	80	15.8	
2 hours	168	28.6	132	26.0	
3 hours	84	14.3	78	15.4	
4 hours	106	18.0	92	18.2	
5 hours	35	6.0	45	8.9	
6 hours	45	7.7	53	10.5	
Number of sunburns in past 12 months					<0.0001
0	472	79.9	320	63.0	
1	92	15.6	121	23.8	
2	19	3.2	47	9.3	
3	6	1.0	11	2.2	
4	0	0.0	3	0.6	
5 or more	2	0.3	6	1.2	
Use of tanning bed in past 12 months					<0.0001
No	583	98.8	478	93.9	
Yes	7	1.2	31	6.1	
Wear sunscreen					<0.0001
Never	33	5.6	75	14.7	
Rarely	62	10.5	109	21.4	
Sometimes	128	21.7	123	24.2	
Often	180	30.5	138	27.1	
Always	187	31.7	64	12.6	
Wear shirt with sleeves					<0.0001
Never	17	2.9	27	5.3	
Rarely	30	5.1	55	10.8	
Sometimes	90	15.3	92	18.1	
Often	177	30.1	167	32.9	
Always	274	46.6	167	32.9	
Wear a hat with brim					0.0004
Never	145	24.7	180	35.5	
Rarely	116	19.7	101	19.9	
Sometimes	137	23.3	110	21.7	
Often	127	21.6	84	16.6	
Always	63	10.7	32	6.3	

	Melanoma Survivors		Population Controls		
	N	%	N	%	p-value
Stay in the shade					<0.0001
Never	33	5.6	54	10.6	
Rarely	59	10.1	115	22.6	
Sometimes	210	35.8	198	39.0	
Often	257	43.8	129	25.4	
Always	28	4.8	12	2.4	
Spend time in the sun to get a tan					<0.0001
Never	410	69.6	256	50.4	
Rarely	120	20.4	128	25.2	
Sometimes	49	8.3	86	16.9	
Often	7	1.2	29	5.7	
Always	3	0.5	9	1.8	

Table 26. Sun exposure and protection behaviors compared between melanoma survivors and population controls.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						<0.0001		0.002	0.003
1 hour or less	404	68.6	289	57.0	1.00		1.00		
2 hours or more	185	31.4	218	43.0	0.59 (0.45, 0.76)		0.63 (0.48, 0.84)		
Hours outside in summer - weekend						0.08		0.21	0.23
1 hour or less	150	25.5	107	21.1	1.00		1.00		
2 hours or more	438	74.5	400	78.9	0.77 (0.58, 1.03)		0.82 (0.60, 1.12)		
Sunburns in past 12 months						<0.0001		<0.0001	<0.0001
None	472	79.9	320	63.0	1.00		1.00		
1 or more	119	20.1	188	37.0	0.39 (0.30, 0.52)		0.37 (0.28, 0.50)		
Tanning bed use in past 12 months						0.0001		0.0001	0.0004
No	583	98.8	478	93.9	1.00		1.00		
Yes	7	1.2	31	6.1	0.19 (0.08, 0.45)		0.18 (0.08, 0.44)		
Wear sunscreen						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	223	37.8	307	60.3	1.00		1.00		
Often/Always	367	62.2	202	39.7	2.75 (2.13, 3.56)		3.06 (2.27, 4.13)		
Wear shirt with sleeves						0.01		0.0002	0.0006
Never/Rarely/Sometimes	137	23.3	174	34.3	1.00		1.00		
Often/Always	451	76.7	334	65.8	1.81 (1.36, 2.41)		1.79 (1.32, 2.43)		
Wear a hat with brim						<0.0001		0.002	0.004
Never/Rarely/Sometimes	398	67.7	391	77.1	1.00		1.00		
Often/Always	190	32.3	116	22.9	1.62 (1.23, 2.10)		1.57 (1.17, 2.11)		
Stay in the shade						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	302	51.5	367	72.2	1.00		1.00		
Often/Always	285	48.6	141	27.8	2.52 (1.95, 3.27)		2.37 (1.80, 3.11)		
Spend time in the sun to get a tan						<0.0001		<0.0001	<0.0001
Sometimes/Often/Always	59	10.0	124	24.4	1.00		1.00		
Rarely/Never	530	90.0	384	75.6	3.13 (2.20, 4.46)		3.30 (2.26, 4.82)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 27a. Sun exposure and protection behaviors compared between /survivors and /controls - 30-49 years at time of survey.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						0.07		0.15	0.17
1 hour or less	110	76.4	76	65.5	1.00		1.00		
2 hours or more	34	23.6	40	34.5	0.59 (0.34, 1.04)		0.63 (0.34, 1.17)		
Hours outside in summer - weekend						0.28		0.47	0.49
1 hour or less	29	20.1	17	14.7	1.00		1.00		
2 hours or more	115	79.9	99	85.3	0.69 (0.35, 1.35)		0.75 (0.35, 1.63)		
Sunburns in past 12 months						0.004		0.004	0.007
None	90	62.5	51	44.0	1.00		1.00		
1 or more	54	37.5	65	53.0	0.47 (0.28, 0.79)		0.44 (0.25, 0.77)		
Tanning bed use in past 12 months						-		-	-
No	142	98.6	102	87.9	1.00		1.00		
Yes	2	1.4	14	12.1	NE		NE		
Wear sunscreen						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	38	26.4	61	52.6	1.00		1.00		
Often/Always	106	73.6	55	47.4	3.32 (1.93, 5.71)		5.39 (2.70, 10.76)		
Wear shirt with sleeves						0.005		0.009	0.01
Never/Rarely/Sometimes	51	35.4	61	52.6	1.00		1.00		
Often/Always	93	64.6	5	47.4	2.20 (1.27, 3.85)		2.40 (1.24, 4.63)		
Wear a hat with brim						0.02		0.03	0.04
Never/Rarely/Sometimes	114	79.2	104	89.7	1.00		1.00		
Often/Always	30	20.8	12	10.3	2.39 (1.15, 4.97)		2.51 (1.11, 5.69)		
Stay in the shade						0.001		0.002	0.004
Never/Rarely/Sometimes	84	58.3	90	77.6	1.00		1.00		
Often/Always	60	41.7	26	22.4	2.57 (1.47, 4.50)		2.75 (1.46, 5.19)		
Spend time in the sun to get a tan						0.002		0.002	0.004
Sometimes/Often/Always	29	20.1	43	37.1	1.00		1.00		
Rarely/Never	115	79.9	73	62.9	2.58 (1.43, 4.67)		3.03 (1.49, 6.15)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 27b. Sun exposure and protection behaviors compared between survivors and controls - 50-59 years at time of survey.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						0.003		0.03	0.04
1 hour or less	157	74.1	116	60.4	1.00		1.00		
2 hours or more	55	25.9	76	39.6	0.52 (0.34, 0.80)		0.55 (0.33, 0.94)		
Hours outside in summer - weekend						0.73		0.56	0.57
1 hour or less	46	21.7	44	22.9	1.00		1.00		
2 hours or more	166	78.3	148	77.1	1.09 (0.67, 1.78)		1.17 (0.69, 1.99)		
Sunburns in past 12 months						<0.0001		<0.0001	<0.0001
None	181	85.0	115	59.9	1.00		1.00		
1 or more	32	15.0	77	40.1	0.26 (0.16, 0.41)		0.22 (0.13, 0.37)		
Tanning bed use in past 12 months						0.08		-	-
No	210	98.6	184	95.3	1.00		1.00		
Yes	3	1.4	9	4.7	0.31 (0.08, 1.16)		NE		
Wear sunscreen						<0.0001		0.0003	0.0008
Never/Rarely/Sometimes	73	34.3	107	55.4	1.00		1.00		
Often/Always	140	65.7	86	44.6	2.51 (1.65, 3.81)		2.50 (1.52, 4.12)		
Wear shirt with sleeves						0.01		0.0008	0.002
Never/Rarely/Sometimes	49	23.1	68	35.4	1.00		1.00		
Often/Always	163	76.9	124	64.6	1.78 (1.13, 2.82)		1.97 (1.19, 3.25)		
Wear a hat with brim						0.07		0.15	0.17
Never/Rarely/Sometimes	143	67.1	146	76.0	1.00		1.00		
Often/Always	70	32.9	46	24.0	1.51 (0.97, 2.37)		1.44 (0.88, 2.36)		
Stay in the shade						0.002		<0.0001	<0.0001
Never/Rarely/Sometimes	104	48.8	137	71.4	1.00		1.00		
Often/Always	109	51.2	55	28.7	2.73 (1.79, 4.16)		2.78 (1.75, 4.39)		
Spend time in the sun to get a tan						<0.0001		<0.0001	<0.0001
Sometimes/Often/Always	16	7.5	46	24.0	1.00		1.00		
Rarely/Never	197	92.5	146	76.0	3.92 (2.10, 7.31)		4.48 (2.25, 8.91)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 27c. Sun exposure and protection behaviors compared between survivors and controls - 60-72 years at time of survey.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						0.02		0.08	0.10
1 hour or less	137	58.8	97	48.7	1.00		1.00		
2 hours or more	96	41.2	102	51.3	0.64 (0.43, 0.94)		0.67 (0.43, 1.05)		
Hours outside in summer - weekend						0.02		0.07	0.09
1 hour or less	75	32.3	46	23.1	1.00		1.00		
2 hours or more	157	67.7	153	76.9	0.60 (0.38, 0.93)		0.64 (0.39, 1.04)		
Sunburns in past 12 months						0.01		0.01	0.01
None	201	85.9	154	77.0	1.00		1.00		
1 or more	33	14.1	46	23.00	0.52 (0.31, 0.87)		0.50 (0.29, 0.86)		
Tanning bed use in past 12 months						0.06		-	-
No	231	99.1	192	96.0	1.00		1.00		
Yes	2	0.9	8	4.0	0.22 (0.05, 1.06)		NE		
Wear sunscreen						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	112	48.1	139	59.5	1.00		1.00		
Often/Always	121	51.9	61	30.5	2.69 (1.77, 4.07)		3.00 (1.82, 4.94)		
Wear shirt with sleeves						0.08		0.22	0.23
Never/Rarely/Sometimes	37	16.0	45	22.5	1.00		1.00		
Often/Always	195	84.1	155	77.5	1.59 (0.95, 2.65)		1.43 (0.81, 2.50)		
Wear a hat with brim						0.06		0.07	0.09
Never/Rarely/Sometimes	141	61.0	141	70.9	1.00		1.00		
Often/Always	90	39.0	58	29.2	1.50 (0.99, 2.27)		1.52 (0.97, 2.38)		
Stay in the shade						<0.0001		0.0003	0.0008
Never/Rarely/Sometimes	114	49.6	140	70.0	1.00		1.00		
Often/Always	116	50.4	60	30.0	2.40 (1.60, 3.60)		2.26 (1.45, 3.51)		
Spend time in the sun to get a tan						0.0004		0.009	0.01
Sometimes/Often/Always	14	6.0	35	17.5	1.00		1.00		
Rarely/Never	218	94.0	165	82.5	3.36 (1.71, 6.59)		3.28 (1.56, 6.92)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 28a. Sun exposure and protection behaviors compared between survivors and controls - males.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						0.04		0.14	0.16
1 hour or less	136	59.7	96	49.5	1.00		1.00		
2 hours or more	92	40.4	98	50.5	0.66 (0.45, 0.98)		0.71 (0.44, 1.12)		
Hours outside in summer - weekend						0.04		0.08	0.10
1 hour or less	44	19.3	23	11.9	1.00		1.00		
2 hours or more	184	80.7	171	88.1	0.56 (0.32, 0.96)		0.59 (0.33, 1.07)		
Sunburns in past 12 months						<0.0001		<0.0001	0.0001
None	177	77.0	114	58.8	1.00		1.00		
1 or more	53	23.0	80	41.2	0.40 (0.26, 0.62)		0.38 (0.24, 0.60)		
Tanning bed use in past 12 months						0.12		-	-
No	227	99.1	189	96.9	1.00		1.00		
Yes	2	0.9	6	3.1	0.28 (0.06, 1.40)		NE		
Wear sunscreen						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	115	50.2	148	75.9	1.00		1.00		
Often/Always	114	49.8	47	24.1	3.18 (2.08, 4.86)		3.65 (2.18, 6.11)		
Wear shirt with sleeves						0.007		0.007	0.01
Never/Rarely/Sometimes	17	7.4	31	15.9	1.00		1.00		
Often/Always	212	92.6	164	84.1	2.35 (1.26, 4.40)		2.52 (1.28, 4.95)		
Wear a hat with brim						0.001		0.005	0.008
Never/Rarely/Sometimes	126	55.3	137	70.3	1.00		1.00		
Often/Always	102	44.7	58	29.7	1.94 (1.29, 2.90)		1.86 (1.21, 2.88)		
Stay in the shade						0.0004		0.005	0.008
Never/Rarely/Sometimes	136	59.7	148	75.9	1.00		1.00		
Often/Always	92	40.4	47	24.1	2.14 (1.40, 3.27)		1.90 (1.21, 2.98)		
Spend time in the sun to get a tan						0.0002		0.0006	0.001
Sometimes/Often/Always	12	5.2	33	16.9	1.00		1.00		
Rarely/Never	217	94.8	162	83.1	3.69 (1.85, 7.37)		3.67 (1.75, 7.70)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 28b. Sun exposure and protection behaviors compared between survivors and controls - females.

	Melanoma Survivors		Controls		Sex and age-adjusted		Fully adjusted*		
	N	%	N	%	OR (95% CI)	p-value	OR (95% CI)	p-value	Adj p-value**
Hours outside in summer - weekdays						0.0003		0.005	0.008
1 hour or less	252	75.2	192	62.3	1.00		1.00		
2 hours or more	83	24.8	116	37.7	0.54 (0.38, 0.75)		0.60 (0.41, 0.86)		
Hours outside in summer - weekend						0.49		0.80	0.80
1 hour or less	99	29.6	83	27.0	1.00		1.00		
2 hours or more	235	70.4	225	73.1	0.88 (0.62, 1.25)		0.95 (0.66, 1.38)		
Sunburns in past 12 months						<0.0001		<0.0001	<0.0001
None	275	82.1	202	65.4	1.00		1.00		
1 or more	60	17.9	107	34.6	0.39 (0.26, 0.57)		0.35 (0.23, 0.52)		
Tanning bed use in past 12 months						0.0004		0.0002	0.0006
No	330	98.5	285	91.9	1.00		1.00		
Yes	5	1.5	25	8.1	0.17 (0.07, 0.46)		0.14 (0.05, 0.39)		
Wear sunscreen						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	96	28.7	155	50.0	1.00		1.00		
Often/Always	239	71.3	155	50.0	2.52 (1.82, 3.49)		2.97 (2.03, 4.34)		
Wear shirt with sleeves						0.002		0.004	0.007
Never/Rarely/Sometimes	111	33.3	140	45.3	1.00		1.00		
Often/Always	222	66.7	169	54.7	1.69 (1.22, 2.35)		1.68 (1.18, 2.39)		
Wear a hat with brim						0.11		0.13	0.15
Never/Rarely/Sometimes	253	75.8	250	81.2	1.00		1.00		
Often/Always	81	24.3	58	18.8	1.37 (0.94, 2.02)		1.38 (0.91, 2.09)		
Stay in the shade						<0.0001		<0.0001	<0.0001
Never/Rarely/Sometimes	151	45.4	215	69.6	1.00		1.00		
Often/Always	182	54.7	94	30.4	2.78 (2.00, 3.85)		2.69 (1.90, 3.81)		
Spend time in the sun to get a tan						<0.0001		0.0002	0.0006
Sometimes/Often/Always	42	15.6	90	29.1	1.00		1.00		
Rarely/Never	292	87.4	219	70.9	2.97 (1.96, 4.51)		3.48 (2.19, 5.54)		

*adjusted for sex, age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

** adjusted for multiple statistical tests using the Benjamini and Hochberg method¹⁸⁹

Table 29a. Sun exposure and protection behaviors compared between survivors with Stage I disease and controls.

	Stage I		Population Controls		Fully adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.02
1 hour or less	324	68.5	289	57.0	1.00	
2 hours or more	149	31.5	218	43.0	0.69 (0.51, 0.93)	
Hours outside in summer - weekend						0.29
1 hour or less	123	26.1	107	21.1	1.00	
2 hours or more	349	73.9	400	78.9	0.84 (0.61, 1.16)	
Sunburns in past 12 months						<0.0001
None	380	80.2	320	63.0	1.00	
1 or more	94	19.8	188	37.0	0.37 (0.27, 0.52)	
Tanning bed use in past 12 months						0.0004
No	467	98.7	478	93.9	1.00	
Yes	6	1.3	31	6.1	0.19 (0.08, 0.48)	
Wear sunscreen						<0.0001
Never/Rarely/Sometimes	171	36.2	307	60.3	1.00	
Often/Always	302	63.9	202	39.7	3.32 (2.41, 4.58)	
Wear shirt with sleeves						0.0007
Never/Rarely/Sometimes	113	24.0	174	34.3	1.00	
Often/Always	358	76.0	334	65.8	1.75 (1.27, 2.41)	
Wear a hat with brim						0.01
Never/Rarely/Sometimes	325	68.9	391	77.1	1.00	
Often/Always	147	31.1	116	22.9	1.49 (1.09, 2.04)	
Stay in the shade						<0.0001
Never/Rarely/Sometimes	242	51.4	367	72.2	1.00	
Often/Always	229	48.6	141	27.8	2.33 (1.75, 3.12)	
Spend time in the sun to get a tan						<0.0001
Sometimes/Often/Always	49	10.4	124	24.4	1.00	
Rarely/Never	423	89.6	384	75.6	3.28 (2.18, 4.93)	

*adjusted for age, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 29b. Sun exposure and protection behaviors compared between survivors with Stage II/III/IV disease and controls.

	Stages II/III/IV		Population Controls		Fully adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.02
1 hour or less	51	69.9	289	57.0	1.00	
2 hours or more	22	30.1	218	43.0	0.46 (0.24, 0.86)	
Hours outside in summer - weekend						0.70
1 hour or less	15	20.6	107	21.1	1.00	
2 hours or more	58	79.5	400	78.9	0.88 (0.45, 1.70)	
Sunburns in past 12 months						0.0002
None	60	81.1	320	63.0	1.00	
1 or more	14	18.9	188	37.0	0.26 (0.13, 0.52)	
Tanning bed use in past 12 months						-
No	74	100.0	478	93.9	1.00	
Yes	0	0.0	31	6.1	NE	
Wear sunscreen						0.0004
Never/Rarely/Sometimes	29	39.2	307	60.3	1.00	
Often/Always	45	60.8	202	39.7	3.28 (1.71, 6.32)	
Wear shirt with sleeves						0.02
Never/Rarely/Sometimes	13	17.6	174	34.3	1.00	
Often/Always	61	82.4	334	65.8	2.42 (1.18, 4.95)	
Wear a hat with brim						0.02
Never/Rarely/Sometimes	44	60.3	391	77.1	1.00	
Often/Always	29	39.7	116	22.9	1.99 (1.11, 3.58)	
Stay in the shade						0.0006
Never/Rarely/Sometimes	37	50.7	367	72.2	1.00	
Often/Always	36	49.3	141	27.8	2.62 (1.51, 4.55)	
Spend time in the sun to get a tan						0.002
Sometimes/Often/Always	5	6.7	124	24.4	1.00	
Rarely/Never	69	93.2	384	75.6	5.66 (1.93, 16.64)	

*adjusted for age, sex, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 30a. Sun exposure and protection behaviors compared between survivors with head/neck tumors and controls.

	Head/Neck Melanoma		Population Controls		Adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.12
1 hour or less	41	65.1	289	57.0	1.00	
2 hours or more	22	34.9	218	43.0	0.59 (0.30, 1.16)	
Hours outside in summer - weekend						0.59
1 hour or less	10	15.9	107	21.1	1.00	
2 hours or more	53	84.1	400	78.9	1.24 (0.57, 2.71)	
Sunburns in past 12 months						0.02
None	48	76.2	320	63.0	1.00	
1 or more	15	23.8	188	37.0	0.45 (0.23, 0.89)	
Tanning bed use in past 12 months						-
No	62	98.4	478	93.9	1.00	
Yes	1	1.6	31	6.1	NE	
Wear sunscreen						<0.0001
Never/Rarely/Sometimes	26	41.3	307	60.3	1.00	
Often/Always	37	58.7	202	39.7	4.17 (2.06, 8.46)	
Wear shirt with sleeves						0.64
Never/Rarely/Sometimes	14	22.2	174	34.3	1.00	
Often/Always	49	77.8	334	65.8	1.19 (0.57, 2.52)	
Wear a hat with brim						0.43
Never/Rarely/Sometimes	40	63.5	391	77.1	1.00	
Often/Always	23	36.5	116	22.9	1.30 (0.68, 2.50)	
Stay in the shade						0.001
Never/Rarely/Sometimes	31	49.2	367	72.2	1.00	
Often/Always	32	50.8	141	27.8	2.75 (1.49, 5.07)	
Spend time in the sun to get a tan						0.14
Sometimes/Often/Always	8	12.7	124	24.4	1.00	
Rarely/Never	55	87.3	384	75.6	1.91 (0.81, 4.50)	

*adjusted for age, sex, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 30b. Sun exposure and protection behaviors compared between survivors with trunk tumors and controls.

	Trunk Melanoma		Population Controls		Adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.07
1 hour or less	131	65.2	289	57.0	1.00	
2 hours or more	70	34.8	218	43.0	0.69 (0.47, 1.03)	
Hours outside in summer - weekend						0.40
1 hour or less	48	24.0	107	21.1	1.00	
2 hours or more	152	76.0	400	78.9	0.83 (0.53, 1.29)	
Sunburns in past 12 months						<0.0001
None	159	78.3	320	63.0	1.00	
1 or more	44	21.7	188	37.0	0.37 (0.24, 0.57)	
Tanning bed use in past 12 months						-
No	202	99.5	478	93.9	1.00	
Yes	1	0.5	31	6.1	NE	
Wear sunscreen						<0.0001
Never/Rarely/Sometimes	79	38.9	307	60.3	1.00	
Often/Always	124	61.1	202	39.7	4.06 (2.60, 6.35)	
Wear shirt with sleeves						0.04
Never/Rarely/Sometimes	48	23.8	174	34.3	1.00	
Often/Always	154	76.2	334	65.8	1.57 (1.02, 2.43)	
Wear a hat with brim						0.008
Never/Rarely/Sometimes	133	65.5	391	77.1	1.00	
Often/Always	70	34.5	116	22.9	1.71 (1.15, 2.54)	
Stay in the shade						0.0008
Never/Rarely/Sometimes	118	58.1	367	72.2	1.00	
Often/Always	85	41.9	141	27.8	1.91 (1.31, 2.78)	
Spend time in the sun to get a tan						<0.0001
Sometimes/Often/Always	16	7.9	124	24.4	1.00	
Rarely/Never	187	92.1	384	75.6	4.99 (2.59, 9.59)	

*adjusted for age, sex, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 30c. Sun exposure and protection behaviors compared between survivors with upper limb tumors and controls.

	Upper limb Melanoma		Population Controls		Adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.01
1 hour or less	109	68.6	289	57.0	1.00	
2 hours or more	50	31.5	218	43.0	0.58 (0.37, 0.90)	
Hours outside in summer - weekend						0.18
1 hour or less	44	27.7	107	21.1	1.00	
2 hours or more	115	72.3	400	78.9	0.73 (0.47, 1.15)	
Sunburns in past 12 months						<0.0001
None	130	81.8	320	63.0	1.00	
1 or more	29	18.2	188	37.0	0.31 (0.19, 0.51)	
Tanning bed use in past 12 months						-
No	157	98.7	478	93.9	1.00	
Yes	2	1.3	31	6.1	NE	
Wear sunscreen						<0.0001
Never/Rarely/Sometimes	63	39.6	307	60.3	1.00	
Often/Always	96	60.4	202	39.7	3.47 (2.20, 5.48)	
Wear shirt with sleeves						0.002
Never/Rarely/Sometimes	31	19.5	174	34.3	1.00	
Often/Always	128	80.5	334	65.8	2.18 (1.33, 3.57)	
Wear a hat with brim						0.02
Never/Rarely/Sometimes	102	64.6	391	77.1	1.00	
Often/Always	56	35.4	116	22.9	1.72 (1.11, 2.66)	
Stay in the shade						<0.0001
Never/Rarely/Sometimes	79	50.0	367	72.2	1.00	
Often/Always	79	50.0	141	27.8	2.61 (1.73, 3.93)	
Spend time in the sun to get a tan						<0.0001
Sometimes/Often/Always	15	9.4	124	24.4	1.00	
Rarely/Never	144	90.6	384	75.6	3.62 (1.90, 6.91)	

*adjusted for age, sex, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 30d. Sun exposure and protection behaviors compared between survivors with lower limb tumors and controls.

	Lower limb Melanoma		Population Controls		Adjusted*	
	N	%	N	%	OR (95% CI)	p-value
Hours outside in summer - weekdays						0.05
1 hour or less	117	74.5	289	57.0	1.00	
2 hours or more	40	25.5	218	43.0	0.63 (0.40, 0.99)	
Hours outside in summer - weekend						0.56
1 hour or less	45	28.7	107	21.1	1.00	
2 hours or more	112	71.3	400	78.9	0.88 (0.56, 1.38)	
Sunburns in past 12 months						<0.0001
None	128	81.5	320	63.0	1.00	
1 or more	29	18.5	188	37.0	0.35 (0.21, 0.58)	
Tanning bed use in past 12 months						-
No	153	98.1	478	93.9	1.00	
Yes	3	1.9	31	6.1	NE	
Wear sunscreen						0.0003
Never/Rarely/Sometimes	52	33.3	307	60.3	1.00	
Often/Always	104	66.7	202	39.7	2.35 (1.48, 3.74)	
Wear shirt with sleeves						0.02
Never/Rarely/Sometimes	40	25.8	174	34.3	1.00	
Often/Always	115	74.2	334	65.8	1.71 (1.09, 2.71)	
Wear a hat with brim						0.25
Never/Rarely/Sometimes	114	73.6	391	77.1	1.00	
Often/Always	41	26.5	116	22.9	1.32 (0.82, 2.11)	
Stay in the shade						<0.0001
Never/Rarely/Sometimes	70	45.5	367	72.2	1.00	
Often/Always	84	54.6	141	27.8	2.52 (1.67, 3.80)	
Spend time in the sun to get a tan						0.001
Sometimes/Often/Always	19	12.3	124	24.4	1.00	
Rarely/Never	136	87.7	384	75.6	2.55 (1.44, 4.52)	

*adjusted for age, sex, education, income, smoking status, phenotypic risk group, personal history of other skin cancer, family history of melanoma, and lifetime sun exposure, outdoor activities, mean sunscreen and sunburns reported prior to diagnosis or reference date.

Table 31. Self-reported changes in avoidance of sun exposure since diagnosis among melanoma survivors.

	More		Same		Less		Never my habit		
	N	%	N	%	N	%	N	%	p-value
All melanoma survivors	448	79.6	84	14.9	19	3.4	12	2.1	
Sex									0.001
Male	164	71.6	48	21.0	10	4.4	7	3.1	
Female	284	85.0	36	10.8	9	2.7	5	1.5	
Age at survey									0.27
30-39	34	79.1	9	20.9	0	0.0	0	0.0	
40-49	79	78.2	17	16.8	3	3.0	2	2.0	
50-59	177	83.1	22	10.3	7	3.3	7	3.3	
60-72	176	75.9	41	17.7	11	4.7	4	1.7	
Melanoma Stage									0.55
I	373	78.8	72	15.3	15	3.2	13	2.8	
II	29	82.9	4	11.4	2	5.7	0	0.0	
III/IV	35	89.7	3	7.7	1	2.6	0	0.0	
Tumor Site									0.02
Head/neck	43	68.3	10	15.9	5	7.9	5	7.9	
Trunk	162	79.8	33	16.3	5	2.5	3	1.5	
Upper limb	123	77.4	25	15.7	7	4.4	4	2.5	
Lower limb	130	83.9	21	13.6	3	1.9	1	0.7	

Table 32. Self-reported changes in wearing of sun protective clothing since diagnosis among melanoma survivors.

	More		Same		Less		Never my habit		
	N	%	N	%	N	%	N	%	p-value
All melanoma survivors	351	62.5	132	23.5	4	0.7	75	13.4	
Sex									0.004
Male	148	64.6	63	27.5	1	0.4	17	7.4	
Female	203	61.0	69	20.7	3	0.9	58	17.4	
Age at survey									0.02
30-39	21	48.8	10	23.3	0	0.0	12	27.9	
40-49	60	59.4	26	25.7	0	0.0	15	14.9	
50-59	129	60.9	49	23.1	0	0.0	34	16.0	
60-72	153	66.0	55	23.7	4	1.7	20	8.6	
Melanoma Stage									0.75
I	292	62.0	102	21.7	4	0.9	73	15.5	
II	21	60.0	10	28.6	0	0.0	4	11.4	
III/IV	27	69.2	9	23.1	0	0.0	3	7.7	
Tumor Site									0.75
Head/neck	33	52.4	20	31.8	0	0.0	4	15.9	
Trunk	131	64.9	40	19.8	2	1.0	29	14.4	
Upper limb	97	61.0	39	24.5	1	0.6	22	13.8	
Lower limb	99	63.9	37	23.9	1	0.7	18	11.6	

Table 33. Self-reported changes in sunscreen use since diagnosis among melanoma survivors.

	More		Same		Less		Never my habit		
	N	%	N	%	N	%	N	%	p-value
All melanoma survivors	440	78.2	95	16.9	3	0.5	25	4.4	
Sex									<0.0001
Male	157	68.9	52	22.8	1	0.4	18	7.9	
Female	282	84.5	43	12.8	2	0.6	7	2.1	
Age at survey									<0.0001
30-39	41	95.4	2	4.7	0	0.0	0	0.0	
40-49	90	89.1	11	10.9	0	0.0	0	0.0	
50-59	166	77.9	38	17.8	2	0.9	7	3.3	
60-72	159	68.5	50	21.6	2	0.9	21	9.1	
Melanoma Stage									0.54
I	372	78.7	75	15.9	4	0.9	22	4.7	
II	23	65.7	10	28.6	0	0.0	2	5.7	
III/IV	32	82.1	5	12.8	0	0.0	2	5.1	
Tumor Site									0.08
Head/neck	42	66.7	16	25.4	0	0.0	5	7.9	
Trunk	150	73.9	39	19.2	3	1.5	11	5.4	
Upper limb	126	79.8	26	16.5	0	0.0	6	3.8	
Lower limb	133	85.3	17	10.9	1	0.6	5	3.2	

9 Conclusion

As early detection and treatments improve, cancer survivors will continue to be a growing portion of the population and an understanding of their needs and concerns is necessary to improve their QOL. The overarching goal of this dissertation was to document the long-term effects of a melanoma diagnosis and treatment on survivors and compare their QOL and health behaviors with population controls.

The experiences shared by participants in the focus groups highlighted a number of QOL issues facing melanoma survivors, including a level of isolation and loneliness that underscores the need to increase both awareness of melanoma and chances for survivors to interact and support each other. In the subsequent cross-sectional study of longer-term melanoma survivors compared to population controls, however, melanoma survivors reported similar QOL and mental health measures as controls. This suggests that melanoma survivors are doing well in general, though future investigation into the disease-specific QOL data collected in the study that was not analyzed as part of this dissertation will help elucidate whether identification of potential risk factors of long-term poor QOL outcomes are needed.

Melanoma survivors reported greater use of sun protection behaviors than controls, however they had similar weekend sun exposure and while less than controls, a significant subgroup experienced sunburns in the past year. The next step is to understand what barriers exist which prevent melanoma survivors from discontinuing risky sun exposure, with the ultimate goal of developing an easily disseminated intervention to address these barriers and promote behavior change.

The studies conducted as part of this dissertation fill gaps in the literature regarding descriptions of the physical, emotional and social health and behaviors of long-term melanoma survivors and specifically the differences between long-term melanoma survivors and population controls. The knowledge gained here serves as the platform from which interventions can be designed to improve the experience of melanoma survivors.

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11 Appendices

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Appendix A. List of questionnaires considered for inclusion in Melanoma-specific QOL questionnaire

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
ACS SCS-II	Breast, prostate, colorectal, urinary bladder, skin melanoma and uterine cancers	56 + 4 open	Basic demographics, co-morbid conditions, cancer diagnosis and treatment, health insurance, Satisfaction with Life Domains Scale-Cancer, Cancer Problems in Living Scale , Modified Rotterdam Symptom Checklist, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being, Medial Outcomes Study Short Form-36 , Multidimensional Scale of Perceived Social Support, POMS-37, employment, lifestyle behavior scale	¹
State-Trait Anger Expression Inventory	General population	44	Contains Anger Expression Scale (AXS) , Anger-expression in, anger-expression out, anger-control in, anger-control out, state anger, trait anger	^{2,3}
Assessment of Survivor Concerns	Cancer survivors	5	Cancer worry, Health worry	⁴
Beck's Depression Inventory	General population	21	Measures depression – focuses on uncovering severe depression requiring medication/hospitalization	⁵
Body Image and Relationships Scale (BIRS)	Breast cancer survivors	32	Strength and health, social barriers, appearance and sexuality	⁶
Brief Fatigue Inventory	Psychiatric patients, cancer patients, normal volunteers	4	Fatigue	⁷
Brief Pain Inventory	Breast, prostate, colorectal and gynecologic cancer and arthritis	9	Pain	⁸
Brief Symptom Inventory	General population	53	Psychological Problems – Subscales: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism. Developed as shorter version of SCL-90R	⁹
Cancer Problems in Living Scale (CPILS)	BMT	29	Quality of life – wide range of questions	¹⁰

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
Cancer Rehabilitation Evaluation Scale (CARES) – Short form	Lung, prostate, colorectal, breast	59 + Open	Physical, Psychosocial, Medical interaction, marital, sexual, other cancer-related items	¹¹
Cancer Survivor's Unmet Needs (CaSUN)	Breast, gynecologic, prostate, colorectal, other	42 + 1 open	Information needs and medical care, quality of life, emotional and relationship issues, life perspective, positive changes	¹²
Cassileth Scar questionnaire	Melanoma	12 + body drawing for location of scar	Patient opinions regarding size and cosmetic implications of their excisions	¹³
CES-D	General population, psychiatric patients	20	Depression – six scales: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, sleep disturbance	¹⁴
Chronic Strains Survey	Breast cancer and melanoma survivors	13	Subjective burden of many strains, from 1 (mildly burdensome) to 3 (extremely burdensome)	¹⁵
Cognitive Appraisal of Health	Breast cancer	28	Threat, Challenge, Harm/Loss, Benign/Irrelevant	¹⁶
Daily Fatigue Impact Scale (D-FIS)	Patients with hypertension, MS or Chronic Fatigue Syndrome, flu	8	Fatigue	¹⁷
Dealing with Illness Coping Inventory	AIDS, used in cancer as well	48	Cognitive and behavioral responses to cope with illness. Eight coping strategies: active-positive, active-expressive, active-reliance, cognitive-positive, cognitive-passive, avoidance-solitary, distraction, and passive-resignation	¹⁸
Depression scale (DEPS)		10	Developed to screen for depression in Finnish primary health-care settings	¹⁹
Dermatology Life Quality Index	Atopic eczema, psoriasis, generalized pruritus, acne, basal cell carcinomas, viral warts	10	Impairment of skin-related quality of life	²⁰

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
Dermatology Quality of Life Scale	Psoriasis, eczema, acne, disorder of keratinization, benign and malignant tumors, pigmentation, alopecia, other conditions	41	Dermatologic symptoms, physical activities, psychosocial state	²¹
Dermatology Specific Quality of Life	Contact dermatitis, acne	36 + 8 global	Symptoms, daily activities, social functioning, work/school performance, personal perceptions	²²
DS14 – Type D personality	Coronary heart disease, hypertension	14	Negative Affectivity (dysphoria, worry, irritability), Social Inhibition (discomfort in social situations, reticence, lack of social poise), Type D personality	²³
EORTC QLQ-C30	Cancer specific, not specified	30	Physical, role , cognitive, emotional, social, fatigue, pain, nausea/vomiting	²⁴
FACT-M	All types / Melanoma-specific	27 / 24	Physical, social/family, emotional, functional, melanoma-specific (pain, skin, physical, fatigue), swelling/issues at surgery site	²⁵
F-COPES	General population?	30	Measures internal and external family coping mechanisms: acquiring social support, reframing, seeking spiritual support, mobilizing the family to acquire and accept help, passive appraisal	²⁶
Fear of Cancer Recurrence Inventory	Prostate, breast, lung, colorectal	42	Fear of cancer recurrence – triggers, severity, psychological distress, coping strategies, functioning impairments, insight, reassurance	²⁷
Functional Living Index – Cancer	Cancer-specific, not specified	22	Physical well-being and ability, emotional state factor	²⁸
General Coping Strategies Scale (COPE)		60	Positive reinterpretation and growth, mental disengagement, focus on and venting of emotions, use of instrumental social support, active coping, denial, religious coping, humor, behavioral disengagement, restraint, use of emotional social support, substance use, acceptance, suppression of competing activities, planning	²⁹
GHQ-28		28	Four subscales: Anxiety, depression, somatic complaints, social dysfunction	³⁰
Global Assessment of Recent Stress Scale				³¹

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
GLQ-8	Cancer and chemotherapy	8		³²
Groningen Activity Restriction scale	Rheumatoid arthritis	18	Measures physical disability (level of independence)	³³
Hardiness Scale				³⁴
Hornheide questionnaire	Cancer-specific	9	Psychosocial issues of cancer patients	³⁵
Hospital Anxiety and Depression Scale (HADS)	Not cancer-specific, originally developed for use with outpatients attending medical clinics	14	Depression, Anxiety	³⁶
Impact of Cancer	Breast, Colorectal, Lymphoma, Prostate	41	Employment, Life Outlook, Body and Health, Feelings about Cancer, Meaning of Cancer, Social Activities and Relationships	³⁷
Impact of Event Scale (IES)	Not cancer-specific (stressful life events)	15	Intrusion, Avoidance	³⁸
Interpersonal Support Evaluation List (ISEL)		40	Belonging or companionship support, Appraisal, Self-esteem maintenance, Instrumental support	³⁹
Inventory to Diagnose Depression	General population	22	Diagnoses major depression	⁴⁰
Life Experience survey	General population	50	Self-report of positive and negative events experienced over the previous year and perceived stress associated with those events	⁴¹
Locus of Control questionnaire		29	Sense of control over self and life events	⁴²
Long-term Quality of Life (LTQL)	Breast, uterine, cervical, other	34	Somatic concerns, philosophical/spiritual view of life, fitness, social support	⁴³
McGill Pain questionnaire	Many events, including cancer	48	What does pain feel like, how does pain change over time, how strong is pain	⁴⁴
Measure of Body Apperception	Breast cancer	10	Investment in appearance, investment in body integrity – reliance on physical appearance for self-worth	⁴⁵
Medical Coping Modes Questionnaire	Lymphoma, colon, lung cancer	32	3 coping modes: Confrontation, avoidance, acceptance-resignation	⁴⁶
Mental Health Inventory		38	Well-being, distress	⁴⁷

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
Millon Behavioral Medical Diagnostic	Cancer, chronic pain, diabetes, HIV/AIDS, heart disease	165	Response patterns, negative health habits, psychiatric indications, coping styles, stress moderators	⁴⁸
Minnesota Multiphasic Personality Inventory (MMPI)	General population	567	Clinical scales: Hypochondriasis, Depression, Hysteria, Psychopathic Deviate, Masculinity-Femininity, Paranoia, Psychastenia, Schizophrenia, Hypomania, Social Introversion	⁴⁹
MOS – 20 item	Chronic illnesses	20	Physical functioning, role functioning, social functioning, mental health, current health perceptions, pain	⁵⁰
Multidimensional Support Scale	General population	16	Measures availability and adequacy of social support from various sources	⁵¹
Multi-item Measure of Adult Attachment		36	Measures attachment on two dimensions: anxiety and avoidance	⁵²
National Survey of Households Affected by Cancer	Cancer in past 5 years (excluding non-melanoma skin cancer)		Included questions regarding both self and family member living in house cancer diagnoses; interactions with doctors, side effects, self-help and alternative therapies, impact on family members, health insurance and health care costs, impact on work, post-cancer life	⁵³
Nonsolar Tanning Items	Non-cancer	8	Ever use, times and duration of indoor tanning and sunless tanning items	⁵⁴
Patient Health Questionnaire (PHQ-9)	OB-GYN patients, younger population, not cancer specific	9 + 1	Depression	⁵⁵
Patient Satisfaction with Cancer Care	Breast, cervical, colorectal, prostate	18	Satisfaction with cancer care	⁵⁶
Perceived Aim of Treatment	Metastatic melanoma	1	Single item: patient perception of aim of their treatment: complete cure, increased long-term survival, increased short-term survival or reduction of symptoms	⁵⁷
Perceived Stress Scale	General population	4/10/14	Measures perceived stress in past month	⁵⁸
Posttraumatic Growth Inventory	Not cancer-specific	21	Relating to others, new possibilities, personal strength, spiritual change appreciation of life; SF also available (10 items)	^{59,60}

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
Profile of Mood States (POMS)		65 (58 used in scoring)	Related to today/this week/right now; tension/anxiety, depression, anger-hostility, vigor-activity, fatigue, confusion	⁶¹
Psychological Adjustment to Cancer	Any cancer, >19 years old, in active treatment	46	Health-care orientation (perception of services), vocational environment, domestic environment, sexual relationships, extended family relationships, social support, psychological distress	⁶²
Quality of Life in Adult Cancer Survivors (QLACS)	Breast, Bladder, Head and Neck, Gynecologic, Prostate, Colorectal	47	Negative feelings [depression], positive feelings, cognitive problems, pain, sexual interest/function, energy/fatigue, social avoidance, financial problems, benefits, distress-family, appearance, distress-recurrence	⁶³
Quality of Life-Cancer Survivors (QOL-CS)	Breast, lymphoma, ovarian, Hodgkin's, cervical, leukemia, colon, other	41	Physical well-being, psychological well-being, social well-being spiritual well-being, fear distress, spiritual	⁶⁴
Quality of Well-Being	Adults at primary clinic	80	Acute and chronic physical symptoms, mental health symptoms, self care, mobility, physical functioning, performance	⁶⁵
Recent Life Changes Questionnaire (RLCQ)		73	Tracks life changes as a source of stress (usually ask about events in past 6 months or year) Questions resolve around Health, Work, Home and Family, Personal and Social, Financial	⁶⁶
Rotterdam symptom checklist	Female cancers	30+ 8 activities	Cancer-specific tool to measure psychological and physical distress in cancer patients. Physical symptoms, physiological symptoms, activities of daily living	⁶⁷
Satisfaction with Life Domain Scales for Cancer SLDS-C	BMT	17	Relationships, health, appearance, leisure time, ability to eat, physical strength	⁶⁸
SCL-90R symptom checklist	Participants in psychotherapy drug trials	90	9 primary symptom dimensions (somatization, obsessive compulsive, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism) and 3 global indices (global severity index, positive symptom distress index, positive symptom total)	⁶⁹

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
SF-36	General health (not cancer specific)	36	Limitations in physical activities because of health problems, limitations in social activities because of physical or emotional problems, limitations in usual role activities because of physical health problems, bodily pain, general mental health, limitations in usual role activities because of emotional problems, vitality (energy and fatigue), and general health perceptions	⁷⁰
Skin Cancer Index	Non-melanoma skin cancer	15	Emotional, appearance, work/financial, lifestyle/recreation, social/family, physical/functioning	^{71,72}
Skindex-29	Adults with appointments at private dermatology clinics	30	Emotions, symptoms, functioning	⁷³
Social Difficulties Inventory	Oncology clinic	21	Social difficulties – physical ability, providing for family, contact with others	⁷⁴
Social Provisions Scale (SPS)	Not cancer-specific	24	Attachment, Social integration, Reassurance of worth, Reliable alliance, guidance, and opportunity for nurturance	⁷⁵
Social Support Survey	Not cancer specific (designed for ill patients)	19	Physical functioning, role limitations – physical and emotional, pain, mental health, current health, social activity, energy/fatigue, physical symptoms, loneliness, family functioning, family happiness, marital functioning	⁷⁶
State-Trait Anxiety Inventory		20	Assesses state and trait anxiety	⁷⁷
Stress Questionnaire (cognitive appraisal sub-scale)			Confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, positive reappraisal	⁷⁸
Structural-Functional Social Support Scale (SFSS)	Cancer-specific; breast, melanoma	10/10	Number of sources of social support, amount of support from those sources	⁷⁹
Sun Exposure and Sun Protection Measures	Skin cancer and general population	14	Sun habits (exposure and protection) and skin examination	⁸⁰
Survivors Module	Early stage Breast cancer	46		⁸¹

Instrument	Cancer Type(s)	# Items	Topics Covered	Ref.
Systems of Beliefs Inventory	Cancer, malignant melanoma	15	Measure religious and spiritual beliefs and practices and the social support derived from a community sharing those beliefs	⁸²
Ways of Coping Questionnaire	Used in study of melanoma and breast cancer survivors	50	Identify thoughts/actions used to cope with a specific stressor; 8 coping factors: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, positive reappraisal	⁸³
Work Concerns During/After Cancer	Tested in gynecological cancer survivors	81 + 8 open	In depth questions regarding employment both at time of cancer diagnosis and after treatment; health insurance/benefits	⁸⁴

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Appendix B. Pilot Questionnaire and Data Sources.

I. Your Health Habits

Question	Source	Melanoma Survivors	Controls
Physical Activity Habits			
Consider a typical 7-day period (a week) in the past month. How many times on average do you do the following kinds of exercise for more than 15 minutes during your free time and for how long per exercise session? Strenuous (Times, Average time) Moderate (Times, Average time) Mild (Times, Average time)	Godin Leisure Time Exercise questionnaire ¹	X	X
Diet Habits			
How many days per week do you eat at least five (5) servings of vegetables and fruits a day?	American Cancer Society – SCS II ²	X	X
Do you currently take a multi-vitamin?	Iowa Women's Health Study ³	X	X
Do you currently take vitamin D on a regular basis, either as part of a multi-vitamin, calcium supplement, or as its own pill?	Skin Health Study ⁴	X	X
On average, how many days per week do you take vitamin D?	Skin Health Study ⁴	X	X
What is the usual amount you take each day?	Skin Health Study ⁴	X	X
Body Size			
How tall are you? Feet Inches	Skin Health Study ⁴	X	X
What is your current weight in pounds?	Skin Health Study ⁴	X	X
Sun Habits			
In the summer, on average, how many hours are outside per day between 10am and 4pm? ON WEEKDAYS ON WEEKEND DAYS	Glanz, Lazovich ⁵	X	X
In the past 12 months, how many times did you have a red OR painful sunburn that lasted a day or more?	Glanz, Lazovich ⁵	X	X
Think about what you do when you are outside during the summer on a warm sunny day. How often do you... Wear sunscreen? Wear a shirt with sleeves that cover your shoulders? Wear a hat with a wide brim? Stay in the shade or under an umbrella? Spend time in the sun in order to get a tan?	Glanz, Lazovich ⁵	X	X

Question	Source	Melanoma Survivors	Controls
In the last 12 months, have you used a tanning bed or booth with tanning lamps? If yes, how many times?	Glanz, Lazovich ⁵	X	X
In the last 12 months have you or your partner examined your entire body, including your back, for skin cancer? If yes, how many times?	Glanz, Lazovich ⁵	X	X
What is the color of your untanned skin?	Glanz, Lazovich ⁵	X	X
Since your melanoma diagnosis have you been... Avoiding exposure to the sun? Wearing sun-protective clothing? Using sunscreen?	American Cancer Society – SCS II ²	X	
Alcohol Habits			
During the past 30 days, how many days per month did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage or liquor? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine or a drink with one shot of liquor.	BRFSS 2012 ⁶ , <i>modified from days per week or days per month</i>	X	X
During the past 30 days, on the days when you drank, about how many did you drink on the average?	BRFSS 2012 ⁶	X	X
Considering all types of alcoholic beverages, how many times during the past 30 days did you have... 5 or more drinks on one occasion if you are man? 4 or more drinks on one occasion if you are a woman?	BRFSS 2012 ⁶	X	X
Smoking Habits			
Do you currently smoke cigarettes on a regular basis?	American Cancer Society – SCS II ²	X	X
On average, how many packs of cigarettes do you smoke per day now (1 pack=20 cigarettes)?	American Cancer Society – SCS II ²	X	X
Do you currently use any of the following tobacco products on a regular basis?	American Cancer Society – SCS II ²	X	X

II. Your Health Habits

Question	Source	Melanoma Survivors	Controls
Quality of Life			
SF-36-Version 2 (36 questions)	SF-36 ⁷	X	X
Emotional Well-Being			
Hospital Anxiety and Depression Scale (HADS; 14 questions)	HADS ⁸	X	X

III. Health Conditions

Question	Source	Melanoma Survivors	Controls
<p>Has a medical doctor or healthcare professional ever told you that you have any of the following?</p> <ul style="list-style-type: none"> ○ Heart Problems, such as a heart attack, coronary artery disease, congestive heart failure, irregular heartbeat, etc. ○ Hypertension (high blood pressure) ○ Chronic back pain, including sciatica (pain or numbness that travels down your leg to below your knees) ○ Arthritis ○ Stroke, including mini-stroke or blood clots in the brain ○ Severe problems with memory or concentration ○ Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease) ○ Stomach and/or intestinal problems, such as Chron's disease, ulcers, or inflammatory bowel disease ○ Diabetes, high blood sugar, or sugar in urine ○ Depression (feeling sad or blue) that required treatment ○ Anxiety or "nervousness" that required treatment ○ Neuropathy (numbness in both hands or both feet) ○ Melanoma (<i>controls only</i>) ○ Cancer other than melanoma ○ Other: _____ 	American Cancer Society – SCS II ²	X	X
<p>Have any of the following members of your family been diagnosed with melanoma?</p> <ul style="list-style-type: none"> Parents Grandparents Brothers Sisters Children Grandchildren 	Skin Health Study ⁴	X	X

IV. Cancer Experience

Question	Source	Melanoma Survivors	Controls
What year were you first diagnosed with melanoma?	American Cancer Society – SCS II ²	X	
Where on your body was your melanoma found?	American Cancer Society – SCS II ²	X	
What stage was your melanoma?	American Cancer Society – SCS II ²	X	
Please mark all treatment you received when your melanoma was first diagnosed? Surgery to remove melanoma Surgery to remove lymph nodes A skin graft Chemotherapy Radiation treatment Immunotherapy (such as Interferon, vaccines)	American Cancer Society – SCS II ²	X	
Has your doctor ever told you that your melanoma has come back to the same part of your body (recurrence)?	American Cancer Society – SCS II ²	X	
What year was the recurrence?	American Cancer Society – SCS II ² - modified	X	
Has your doctor ever told you that your melanoma has spread to another part of your body (metastasized)?	American Cancer Society – SCS II ²	X	
What year did the melanoma spread?	American Cancer Society – SCS II ²	X	
If your first melanoma returned or spread to another part of your body, which additional treatments have you received? Surgery to remove melanoma Surgery to remove lymph nodes A skin graft Chemotherapy Radiation treatment Immunotherapy (such as Interferon, vaccines)	American Cancer Society – SCS II ²	X	
When you had surgery to remove lymph nodes, how many were removed?	American Cancer Society – SCS II ² - modified	X	
Did you experience swelling or lymphedema lasting greater than 1 month at any point after surgery or radiation treatment?	NEW	X	
When did your swelling or lymphedema first occur?	NEW	X	
How long did the swelling last? Years Months	NEW	X	
Where was your swelling?	NEW	X	
Do you still have swelling?	NEW	X	

Question	Source	Melanoma Survivors	Controls
<p>These questions are about the swelling that you have:</p> <p>I am bothered by the amount of swelling.</p> <p>Movement of my swollen area is painful.</p> <p>Swelling keeps me from doing the things I want to do.</p> <p>Swelling keeps me from wearing clothes or shoes I want to wear.</p>	FACT-M ⁹	X	
Have you ever received or are you currently receiving treatment for your swelling or lymphedema?	NEW	X	
<p>What types of treatment for swelling or lymphedema have you received (check all that apply)?</p> <p>Manual lymphatic drainage</p> <p>Compression</p> <p>Pump</p> <p>Exercise</p> <p>Other: _____</p>	NEW	X	
How helpful have the treatments for your swelling or lymphedema been?	NEW	X	
<p>Please describe how much these concerns affect you.</p> <p>I feel numbness at my surgical site.</p> <p>I have good range of movement in my arms and legs.</p> <p>I am more aware of physical problems or changes in my body since having had melanoma.</p> <p>New symptoms (aches, pains, getting sick) make me worry about the melanoma coming back.</p> <p>I am worried that family members may also develop skin cancer/melanoma.</p> <p>I feel bothered by people's questions related to my melanoma.</p> <p>I am worried about the size of the scar.</p> <p>I think about how my melanoma scar affects my attractiveness.</p> <p>I think about how noticeable the scar is to others.</p> <p>I sometimes wear clothing to cover up my scar.</p>	<p>FACT-M⁹</p> <p>Impact of Cancer¹⁰</p> <p>Skin Cancer Index¹¹ - modified</p> <p>Impact of Cancer¹⁰ - modified</p>	X	

V. Experience with Health Care System

Question	Source	Melanoma Survivors	Controls
When you were diagnosed with melanoma, did the doctor tell you what the likely outcome of having melanoma would be?	National Survey of Households Affected by Cancer ¹²	X	
Did the doctor say the melanoma could be cured or go into long-term remission, or didn't the doctor say that?	National Survey of Households Affected by Cancer ¹²	X	
Did the doctor say the melanoma was likely to be fatal or lead to death?	National Survey of Households Affected by Cancer ¹²	X	
When you first found out you had melanoma, were you mostly optimistic or mostly pessimistic about surviving melanoma?	National Survey of Households Affected by Cancer ¹²	X	
Please rate the doctors and other health professionals seen during the course of your melanoma surgery/treatment: <ul style="list-style-type: none"> • Knowledge and expertise in handling your medical issues • Level of compassion • Attention to factors outside of direct medical care, such as support network for dealing with cancer 	National Survey of Households Affected by Cancer ¹²	X	
When getting care for your melanoma, was there ever a time when <ul style="list-style-type: none"> • Your medical records or test results did not reach your doctor's office in time for your appointment • You were sent for duplicate test or diagnostic procedures by different doctors, nurses or health care workers • You left a doctor's office without getting important questions answered about your care or treatment? • You were confused about the medication the doctor prescribed? • You had to wait longer than you thought to find out results of medical tests? 	National Survey of Households Affected by Cancer ¹²	X	
Did waiting for test results produce stress and anxiety?	National Survey of Households Affected by Cancer ¹²	X	
Did you ever have to make a decision about whether to undergo a treatment that would increase your chances of survival by only a small amount but could potentially lead to severe side effects?	National Survey of Households Affected by Cancer ¹²	X	
Did you decide to undergo the treatment?	National Survey of Households Affected by Cancer ¹²	X	
How satisfied are you with your decision?	NEW	X	
Before your diagnosis, how much did you know about melanoma?	NEW	X	

VI. Work and Insurance

[illegible]

During the time you were treated for melanoma, were you covered by health insurance for all or part of the time? Indicate the source of your health insurance at the time you were treated for melanoma (check all that apply).	National Survey of Households Affected by Cancer ¹²	X	
Do you currently have life insurance?	NEW	X	X
After your melanoma diagnosis, did you experience any of the following problems with a health insurance plan related to your melanoma treatment? Plan would not pay anything for care that you thought was covered Plan paid less than you expected for a bill received from a doctor, hospital, or lab Reached a limit of what the insurance company would pay for cancer treatment Turned away or unable to get specific type of treatment because of insurance issues	National Survey of Households Affected by Cancer ¹²	X	
How much of a burden on your family were the costs of overall medical care related to your melanoma treatment?	National Survey of Households Affected by Cancer ¹²	X	
Did any of the following things happen to you as a result of the financial cost of dealing with melanoma? Used up all or most of your savings Unable to pay for basic necessities like food, heat, or housing Borrowed money from relatives or friends Borrowed money from other sources (such as bank loan, mortgage on your home, against a retirement account) Contacted by a collection agency Declared bankruptcy Sought the aid of a charity or public assistance Lost your health insurance Couldn't buy health insurance because of having melanoma Couldn't buy life insurance because of having melanoma	National Survey of Households Affected by Cancer ¹²	X	

VII. Well-Being Associated with Melanoma Diagnosis

Question	Source	Melanoma Survivors	Controls
How difficult is it for you to cope today as a result of melanoma diagnosis and treatment?	Quality of Life – Cancer Survivors ¹⁵	X	
How good is your quality of life?	Quality of Life – Cancer Survivors ¹⁵	X	
How much happiness do you feel?	Quality of Life – Cancer Survivors ¹⁵	X	
Do you feel like you are in control of things in your life?	Quality of Life – Cancer Survivors ¹⁵	X	
How satisfying is your life?	Quality of Life – Cancer Survivors ¹⁵	X	
How is your present ability to concentrate or to remember things?	Quality of Life – Cancer Survivors ¹⁵	X	
How useful do you feel?	Quality of Life – Cancer Survivors ¹⁵	X	
Has your melanoma diagnosis or treatment caused changes in your appearance?	Quality of Life – Cancer Survivors ¹⁵	X	
Has your illness or treatment caused changes in your self-concept (the way you see yourself)?	Quality of Life – Cancer Survivors ¹⁵	X	
How serious do you consider melanoma to be?	NEW	X	
How distressing were the following aspects of your illness and treatment... Initial Diagnosis Melanoma treatments Time since your treatment was completed How much anxiety do you have? How much depression do you have?	Quality of Life – Cancer Survivors ¹⁵	X	
To what extent are you fearful of... Future diagnostic tests A second melanoma Recurrence of your melanoma Spreading (metastasis) of your melanoma Children/Other Family Members getting melanoma Dying from melanoma	Quality of Life – Cancer Survivors ¹⁵ NEW	X	
How distressing has melanoma been for your family?	Quality of Life – Cancer Survivors ¹⁵	X	
Is the amount of support you receive from others sufficient to meet your needs?	Quality of Life – Cancer Survivors ¹⁵	X	
Is your continuing health care interfering with your personal relationships?	Quality of Life – Cancer Survivors ¹⁵	X	
Is your sexuality impacted by your melanoma?	Quality of Life – Cancer Survivors ¹⁵	X	
To what degree has your melanoma and treatment interfered with your employment?	Quality of Life – Cancer Survivors ¹⁵	X	
To what degree has your melanoma and treatment interfered with your activities at home?	Quality of Life – Cancer Survivors ¹⁵	X	
How much isolation do you feel is caused by your melanoma or treatment?	Quality of Life – Cancer Survivors ¹⁵	X	

Question	Source	Melanoma Survivors	Controls
How much financial burden have you incurred as a result of your melanoma and treatment?	Quality of Life – Cancer Survivors ¹⁵	X	
How frustrated are you that some people do not understand the seriousness of a melanoma diagnosis?	NEW	X	
Because of melanoma, I live each day one at a time.	Impact of Cancer ¹⁰	X	
I feel grateful to be alive.	Impact of Cancer ¹⁰	X	
I feel like time in my life is limited.	Impact of Cancer ¹⁰	X	
I learned something about life because of having had melanoma.	Impact of Cancer ¹⁰	X	
Having had melanoma makes me feel unsure about my future.	Impact of Cancer ¹⁰	X	
I worry about my future.	Impact of Cancer ¹⁰	X	
I am afraid to die.	Impact of Cancer ¹⁰	X	
I can accept my mortality, that I am going to die someday.	Impact of Cancer ¹⁰	X	
I feel like time in my life is running out.	Impact of Cancer ¹⁰	X	
Having had melanoma has made me realize that time is precious.	Impact of Cancer ¹⁰	X	
Having had melanoma has strengthened my religious faith or my sense of spirituality.	Impact of Cancer ¹⁰	X	
I consider myself to be a cancer survivor.	Impact of Cancer ¹⁰	X	
I spend more time with loved ones since my diagnosis.	NEW	X	

VIII. Your Background

Question	Source	Melanoma Survivors	Controls
What is your current age?	Skin Health Study ⁴	X	X
Sex	Skin Health Study ⁴	X	X
Race (select all that apply)	US Census Bureau ¹⁶	X	X
Ethnicity	US Census Bureau ¹⁶	X	X
Education	Skin Health Study ⁴	X	X
Marital Status	Skin Health Study ⁴	X	X
Annual Household Income	Skin Health Study ⁴	X	X

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Appendix C. Online Melanoma Survivor Survey

Skin Health Study - Follow-up Survey

Thank you for being willing to share your experience after a melanoma diagnosis by completing our online survey.

For a better online experience, please use a computer rather than a tablet or smart phone.

Please use the Previous and Next buttons found at the bottom of each page instead of the back and forward arrows on your browser.

For each question, please give the answer that seems to best describe how you feel or what your experience has been like. Some of the survey questions may seem the same, but they are all important to answer.

The reset button can be used to clear your answer(s) if you want to start a question over.

If you do not finish in one sitting, you can close your browser window and come back later to where you left off. To do this:

- Click on Save and Return Later
- You will be given a code, or password, to use upon re-entry
- Use the same web link that was included in your letter for re-entry, click on Returning in the top right corner, then enter the code given

Study ID This number can be found on your letter.

Please Re-Enter Study ID

The Study ID's did not match. Please correct.

Date

((Please click on the 'Now' button))

CONSENT FORM**INTRODUCTION**

You are invited to be in a scientific research study that is being conducted by Dr. DeAnn Lazovich at the University of Minnesota School of Public Health. The purpose of this study is to learn more about the experiences of people with melanoma after diagnosis compared to people without a melanoma diagnosis. The study is funded by the University of Minnesota. You were selected because you previously participated in the Skin Health Study between 2004 and 2009.

STUDY PROCEDURES

If you choose to be in the study, we will ask you to take a one-time online survey. The survey asks about your diagnosis and treatment, current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. The survey will take between 20 and 40 minutes, depending on your medical history.

CONFIDENTIALITY

The records of this study will be kept private and confidential. In any report we might publish, we will not include any information that will make it possible to identify a participant. Every precaution is taken to make sure that all data are kept safe and secure. The online survey uses a secure web interface to protect the data that you enter. Only researchers involved in this project will have access to these data files.

RISKS AND BENEFITS

There are no known risks, except for possible breach of confidentiality. However we will take every precaution to keep your study information confidential. Although there are no direct benefits to you from participating in this study, the information you provide may help us learn about ways to assist persons who have been diagnosed with melanoma.

VOLUNTARY NATURE

Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

WHOM TO CONTACT

If you have any questions about the study, you may contact Dr. Lazovich or her research staff by email (shs@umn.edu) or by phone (612 624-3056). If you have questions or concerns regarding this study and would like to talk to someone other than the researcher (s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at Fairview Research Administration, 2433 Energy Park Drive, St. Paul, MN, 55108.

Statement of consent: Check the appropriate box below

- ☐ I have read the above information. I agree to participate in this study.
☐ I do not agree to participate in the study.

I. Your Health Habits

The first questions are about your physical activity, diet, body size, sun protection, alcohol and smoking habits.

Physical Activity Habits

Consider a typical 7-day period (a week) in the past month.

How many times on average do you do the following kinds of exercise for more than 15 minutes during your free time and for how long per exercise session?

Strenuous activity (heart beats rapidly, heaving sweating)

Examples: running, jogging, hockey, soccer, squash, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling, vigorous aerobic dance classes, heavy weight training.

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Moderate activity (not exhausting, light sweating)

Examples: fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing.

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Mild activity (minimal effort, no sweating)

Examples: easy walking, yoga, archery, fishing, bowling, lawn bowling, shuffleboard, horseshoes, golf, snowmobiling

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Diet Habits

How many days per week do you eat at least five (5) servings of fruits and vegetables a day? One serving = 1 piece of fruit, half a cup of cooked vegetables, or one cup of raw leafy vegetables.

- ☐ 0 days
- ☐ 1 day
- ☐ 2 days
- ☐ 3 days
- ☐ 4 days
- ☐ 5 days
- ☐ 6 days
- ☐ 7 days

Do you currently take a multi-vitamin?

- ☐ Yes
- ☐ No

On average, how many days per week do you take a multivitamin?

- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

Do you currently take vitamin D on a regular basis, either as part of a multi-vitamin, calcium supplement, or as its own pill?

- ☐ Yes
- ☐ No
- ☐ Don't know

On average, how many days per week do you take vitamin D?

- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

What is the usual amount you take each day?

- ☐ Less than 400 IU
- ☐ 400 IU
- ☐ 600 IU
- ☐ 800 IU
- ☐ 1000 IU
- ☐ 2000 IU
- ☐ Greater than 2000 IU
- ☐ Other
- ☐ Unknown

Usual Amount

Body Size

How tall are you?

Feet	<input type="text"/>
	(Feet)
Inches	<input type="text"/>
	(Inches)
What is your current weight in pounds?	<input type="text"/>
	(Pounds)

Sun Habits

In the summer, on average, how many hours are you outside per day between 10 am and 4 pm...

on WEEKDAYS (Monday - Friday)?

- ☐ 0 to 30 minutes
- ☐ 31 minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

on WEEKEND DAYS (Saturday & Sunday)?

- ☐ 0 to 30 minutes
- ☐ 31 minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

In the past 12 months, how many times did you have a red OR painful sunburn that lasted a day or more?

- ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

Sun Habits continued

For the following questions, think about what you typically do when you are outside during the summer on a warm sunny day.

When you are outside during the summer on a warm sunny day, how often do you wear sunscreen ?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you wear a shirt with sleeves that cover your shoulders?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you wear a hat with a wide brim?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you stay in the shade or under an umbrella?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you spend time in the sun in order to get a tan?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

Sun Habits continued

In the last 12 months, have you used a tanning bed or booth with tanning lamps?

☐ Yes ☐ No

How many times in the last 12 months have you used a tanning bed or booth with tanning lamps?

In the last 12 months, have you had your skin checked from head to toe by a health professional?

☐ Yes ☐ No

In the last 12 months have you or a partner examined your entire body, including your back for skin cancer?

☐ Yes ☐ No

How many times?

What is the color of your untanned skin?

☐ Very fair ☐ Fair ☐ Olive
☐ Light brown ☐ Dark brown
☐ Very dark

Since your melanoma diagnosis, have you been...

Avoiding exposure to the sun?

☐ More ☐ Same ☐ Less
☐ Never my habit

Wearing sun-protective clothing?

☐ More
☐ Same
☐ Less
☐ Never my habit

Using sunscreen?

☐ More
☐ Same
☐ Less
☐ Never my habit

Alcohol Habits

During the past 30 days, how many days per month did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage or liquor? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine or a drink with one shot of liquor.

- ☐ none
 - ☐ 1
 - ☐ 2
 - ☐ 3
 - ☐ 4
 - ☐ 5
 - ☐ 6
 - ☐ 7
 - ☐ 8
 - ☐ 9
 - ☐ 10
 - ☐ 11
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 - ☐ 18
 - ☐ 19
 - ☐ 20
 - ☐ 21
 - ☐ 22
 - ☐ 23
 - ☐ 24
 - ☐ 25
 - ☐ 26
 - ☐ 27
 - ☐ 28
 - ☐ 29
 - ☐ 30
- (days per month)

During the past 30 days, on the days when you drank, about how many drinks did you drink on the average?

- ☐ 1 drink
- ☐ 2 drinks
- ☐ 3 drinks
- ☐ 4 drinks
- ☐ 5 drinks
- ☐ 6 drinks
- ☐ 7 drinks
- ☐ 8 drinks
- ☐ 9 drinks
- ☐ 10 drinks
- ☐ 11 drinks
- ☐ 12 drinks
- ☐ more than 12

Considering all types of alcoholic beverages, how many times during the past 30 days did you have... 5 or more drinks on one occasion if you are a man? 4 or more drinks on one occasion if you are a woman?

(times)

Smoking Habits

Do you currently smoke cigarettes on a regular basis?

☐ Yes ☐ No

On average, how many packs of cigarettes do you smoke per day now? (1 pack = 20 cigarettes)

- ☐ Less than ½ pack
☐ ½ pack
☐ 1 pack
☐ 1 ½ packs
☐ 2 packs
☐ more than 2 packs

Do you currently use any of the following tobacco products on a regular basis? Mark all that apply. Mark "none" if you do not use any on a regular basis.

- ☐ None
☐ Cigars
☐ Pipe tobacco
☐ Chewing tobacco
☐ Dip or snuff
☐ Other (please specify)

If Other, please describe

II. Your Health and Well-Being

The next questions ask about your general physical, emotional and social well-being.

In general, would you say your health is:

- ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

Compared to one year ago, how would you rate your health in general now?

- ☐ Much better now than one year ago
☐ Somewhat better now than one year ago
☐ About the same as one year ago
☐ Somewhat worse now than one year ago
☐ Much worse now than one year ago

Your Health and Well-Being continued

The following questions are about activities that you might do during a typical day. Does your health now limit in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	Not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than a mile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did work or other activities less carefully than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

How much bodily pain have you had during the past 4 weeks?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

Your Health and Well-Being continued These next few questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

Your Health and Well-Being continued**How TRUE or FALSE is each of the following statements for you?**

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Emotional Well-Being

The next set of questions will ask you about your emotional well-being.

I feel tense or 'wound up':

- ☐ Most of the time ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all

I still enjoy the things I used to enjoy:

- ☐ Definitely as much ☐ Not quite as much ☐ Only a little ☐ Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly ☐ Yes, but not too badly ☐ A little, but it doesn't worry me
☐ Not at all

I can laugh and see the funny side of things:

- ☐ As much as I always could ☐ Not quite so much now ☐ Definitely not so much now
☐ Not at all

Worry thoughts go through my mind:

- ☐ A great deal of the time ☐ A lot of the time ☐ From time to time, but not too often
☐ Only occasionally

Emotional Well-Being continued

I feel cheerful:

- ☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

I can sit at ease and feel relaxed:

- ☐ Definitely ☐ Usually ☐ Not often ☐ Not at all

I feel restless as if I have to be on the move:

- ☐ Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all

I look forward with enjoyment to things:

- ☐ As much as I ever did ☐ Rather less than I used to ☐ Definitely less than I used to
☐ Hardly at all

I get sudden feelings of panic:

- ☐ Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all

Emotional Well-Being continued

I can enjoy a good book or radio or TV program:

☐ Often ☐ Sometimes ☐ Not often ☐ Very seldom

I feel as if I am slowed down:

☐ Nearly all the time ☐ Very often ☐ Sometimes ☐ Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

III. Health Conditions

Has a medical doctor or healthcare professional ever told you that you have any of the following?

Heart Problems, such as a heart attack, coronary artery disease, congestive heart failure, irregular heartbeat, etc. ☐ Yes ☐ No

Hypertension (high blood pressure) ☐ Yes ☐ No

Chronic back pain, including sciatica (pain or numbness that travels down your leg to below your knees) ☐ Yes ☐ No

Arthritis ☐ Yes ☐ No

Stroke, including mini-stroke or blood clots in the brain ☐ Yes ☐ No

Severe problems with memory or concentration ☐ Yes ☐ No

Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease) ☐ Yes ☐ No

Stomach and/or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease ☐ Yes ☐ No

Health Conditions continued

Has a medical doctor or healthcare professional ever told you that you have any of the following?

Diabetes, high blood sugar, or sugar in urine ☐ Yes ☐ No

Depression (feeling sad or blue) that resulted in treatment with medication and/or counseling ☐ Yes ☐ No

Anxiety or "nervousness" that resulted in treatment with medication and/or counseling ☐ Yes ☐ No

Neuropathy (numbness in both hands or both feet) ☐ Yes ☐ No

Cancer other than melanoma ☐ Yes ☐ No

Please describe

Other health condition(s) ☐ Yes ☐ No

Please describe

Health Conditions continued

Have any of the following members of your family been diagnosed with melanoma?

- | | | | |
|---------------|---------------------------|--------------------------|--------------------------------------|
| Parents | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Grandparents | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Brothers | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Sisters | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Children | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Grandchildren | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |

IV. Cancer Experience

The next questions are about your experience after diagnosis with your FIRST (or only) melanoma.

What year were you first diagnosed with melanoma?

(Enter year)

Where on your body was your melanoma found?

☐ Head or neck ☐ Trunk ☐ Arms ☐ Legs

What stage was your melanoma?

☐ I ☐ II ☐ III ☐ IV
☐ Don't know

Cancer Experience continued

Please mark all treatments you received when your melanoma was first diagnosed:

- | | | | |
|----------------------------------------------|---------------------------|--------------------------|----------------------------------|
| Surgery to remove melanoma | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |
| Surgery to remove lymph nodes | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |
| A skin graft | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |
| Chemotherapy | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |
| Radiation treatment | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |
| Immunotherapy (such as Interferon, vaccines) | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Don't know |

Cancer Experience continued

Has your doctor ever told you that your melanoma has come back to the same part of your body (recurrence)?

☐ Yes ☐ No

What year was the recurrence?

(Enter year)

Has your doctor ever told you that your melanoma has spread to another part of your body (metastasized)?

☐ Yes ☐ No

What year did the melanoma spread?

(Enter year)

If your first melanoma returned or spread to another part of your body, please mark all additional treatments you have received.

Surgery to remove melanoma

☐ Yes ☐ No

Surgery to remove lymph nodes

☐ Yes ☐ No

A skin graft

☐ Yes ☐ No

Chemotherapy

☐ Yes ☐ No

Radiation treatment

☐ Yes ☐ No

Immunotherapy (such as Interferon, vaccines)

☐ Yes ☐ No

Cancer Experience continued

When you had surgery to remove lymph nodes, how many were removed?

- ☐ 1-4 ☐ 5-9 ☐ 10-14
☐ 15+ ☐ Don't Know

Did you experience swelling or lymphedema lasting greater than 1 month at any point after surgery or radiation treatment?

- ☐ Yes ☐ No ☐ Don't Know

When did your swelling or lymphedema FIRST occur?

- ☐ Following treatment of your first melanoma
☐ Following treatment of melanoma that returned to same part of your body
☐ Following treatment of melanoma that spread to other parts of your body

How long did the swelling last?

Years

(Enter number of years or 0 if less than 1 year)

Months

(Enter number of months)

Where on your body was your swelling?

(Write in body location)

Have you received or are currently receiving treatment to PREVENT swelling or lymphedema following your surgery or radiation treatment?

- ☐ Yes ☐ No ☐ Don't know

When did you first begin treatment to prevent swelling or lymphedema?

- ☐ Following treatment of your first melanoma
☐ Following treatment of melanoma that returned to same part of your body
☐ Following treatment of melanoma that spread to other parts of your body

How long did or have the treatments lasted?

Years

(Enter number of years or 0 if less than 1 year)

Months

(Enter number of months)

What part of your body was treated?

(Write in body location)

Cancer Experience continued

Do you still have swelling? ☐ Yes ☐ No

These questions are about the swelling that you have.

I am bothered by the amount of swelling.

☐ Not at all ☐ A little bit ☐ Somewhat ☐ Quite a bit ☐ Very Much

Movement of my swollen area is painful.

☐ Not at all ☐ A little bit ☐ Somewhat ☐ Quite a bit ☐ Very Much

Swelling keeps me from doing the things I want to do.

☐ Not at all ☐ A little bit ☐ Somewhat ☐ Quite a bit ☐ Very Much

Swelling keeps me from wearing clothes or shoes I want to wear.

☐ Not at all ☐ A little bit ☐ Somewhat ☐ Quite a bit ☐ Very Much

Have you received or are you currently receiving treatment for your swelling or lymphedema? ☐ Yes ☐ No

What types of treatment for swelling or lymphedema have you received? (mark all that apply)

- ☐ Manual lymphatic drainage
- ☐ Compression
- ☐ Pump
- ☐ Exercise
- ☐ Other

Please describe other treatment _____

How helpful have the treatments for your swelling or lymphedema been?

☐ Very helpful ☐ Somewhat helpful ☐ A little helpful ☐ Not at all helpful

What types of treatment for prevention of swelling or lymphedema have you received? (mark all that apply)

- ☐ Manual lymphatic drainage
- ☐ Compression
- ☐ Pump
- ☐ Exercise
- ☐ Other

Please describe other treatment _____

How helpful have the treatments been for preventing swelling or lymphedema?

☐ Very helpful ☐ Somewhat helpful ☐ A little helpful ☐ Not at all helpful

Cancer Experience continued**Please describe how much these concerns affect you.**

	Not at all	A little bit	Somewhat	Quite a bit	Very Much
I feel numbness at my surgical site.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have good range of movement in my arms and legs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am more aware of physical problems or changes in my body since having had melanoma.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New symptoms (aches, pains, getting sick) make me worry about the melanoma coming back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried that family members may also develop skin cancer/melanoma.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel bothered by people's questions related to my melanoma.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about the size of the scar.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think about how my melanoma scar affects my attractiveness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think about how noticeable the scar is to others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes wear clothing to cover up my scar.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

V. Experience with Health Care System

These questions ask about your experience with the health care professionals who took care of you at the time you were first diagnosed with melanoma.

When you were first diagnosed with melanoma, did the doctor tell you what the likely outcome of having melanoma would be? ☐ Yes ☐ No ☐ Don't know

Did the doctor say the melanoma could be cured or go into long-term remission? ☐ Yes ☐ No ☐ Don't know

Did the doctor say the melanoma was likely to be fatal or lead to death? ☐ Yes ☐ No ☐ Don't know

When you first found out you had melanoma, were you mostly optimistic or mostly pessimistic about surviving melanoma?

☐ Mostly optimistic ☐ Mostly pessimistic ☐ Don't know

Before your diagnosis, how much did you know about melanoma?

☐ Nothing ☐ Very little ☐ Some ☐ Quite a bit ☐ A lot

Experience with Health Care System continued

Please rate the doctors and other health professionals seen during the course of your treatment:

Knowledge and expertise in handling your medical issues ☐ Excellent ☐ Good ☐ Fair
☐ Poor

Level of compassion ☐ Excellent ☐ Good ☐ Fair
☐ Poor

Attention to factors outside of direct medical care, such as support network for dealing with melanoma ☐ Excellent ☐ Good ☐ Fair
☐ Poor

During the course of your first melanoma treatment, did you receive conflicting information about melanoma from different doctors or health care professionals? ☐ Yes ☐ No ☐ Don't know

Experience with Health Care System continued

When getting care for your melanoma, was there ever a time when...

Your medical records or test results did not reach your doctor's office in time for your appointment? ☐ Yes ☐ No ☐ Not applicable

You were sent for duplicate test or diagnostic procedures by different doctors, nurses or health care workers? ☐ Yes ☐ No

You left a doctor's office without getting important questions answered about your care or treatment? ☐ Yes ☐ No

You were confused about the medication the doctor prescribed? ☐ Yes ☐ No ☐ Not applicable

You had to wait longer than you thought you should to find out results of medical tests? ☐ Yes ☐ No

Did waiting for test results produce stress and anxiety? ☐ Yes, a lot ☐ Just some ☐ No

Experience with Health Care System continued

Did you ever have to make a decision about whether to undergo a treatment that would increase your chances of survival by only a small amount but could potentially lead to severe side effects?

☐ Yes ☐ No ☐ Don't know

Did you decide to undergo the treatment?

☐ Yes ☐ No ☐ Don't know

How satisfied are you with your decision?

☐ Not at all ☐ A little bit ☐ Somewhat ☐ Quite a bit ☐ Very Much

VI. Work and Insurance

The next questions are about work and insurance.

What is your CURRENT employment status? If more than one category applies, please choose the one that best describes your current employment status.

- ☐ Paid full-time employment
- ☐ Paid part-time employment
- ☐ Self-employed
- ☐ Volunteer
- ☐ Homemaker
- ☐ Unemployed, looking for work
- ☐ Unemployed, not looking for work
- ☐ Not employed - disabled
- ☐ Retired, not working
- ☐ Student, not working

During the past 12 months, about how many days did you miss work at your job or business because of illness (do not include maternity leave)?

(days)

During the past 12 months, about how many days did illness keep you in bed more than half of the day (include days while an overnight patient in a hospital)?

(days)

Work and Insurance continued

At the time you were FIRST DIAGNOSED with melanoma, what was your employment status? If more than one category applies, please choose the one that best describes your employment status when you were first diagnosed.

- ☐ Paid full-time employment
- ☐ Paid part-time employment
- ☐ Self-employed
- ☐ Volunteer
- ☐ Homemaker
- ☐ Unemployed, looking for work
- ☐ Unemployed, not looking for work
- ☐ Not employed - disabled
- ☐ Retired, not working
- ☐ Student, not working

At the time you were diagnosed with melanoma, were you offered the following benefits from your main employer? (or yourself if self-employed)

- | | |
|--------------------------------|-----------------------------------------------------------------------------------------|
| Paid sick time | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Applicable |
| Paid vacation | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Applicable |
| Unpaid time off | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Applicable |
| Short-term disability coverage | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Applicable |
| Long-term disability coverage | <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not Applicable |

Since being diagnosed with melanoma, did you miss any days from work because of your melanoma (either for treatment, rest, side-effects of treatment)?

- ☐ Yes ☐ No

Approximately how many days did you miss?

_____ (days)

How well did your employer treat you during your experience with melanoma?

- ☐ Very well ☐ Somewhat well ☐ Not too well ☐ Not well at all

Work and Insurance continued

Have any of the following things happened to you since you were diagnosed with melanoma?

- | | | | |
|--------------------------------------------|---------------------------|--------------------------|--------------------------------------|
| You were laid off or fired? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| Your responsibilities on the job were cut? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were passed over for a raise? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were passed over for a promotion? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| Your salary was reduced? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were demoted? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |

Work and Insurance continued

Have any of the following things happened to you since you were diagnosed with melanoma?

- | | | | |
|---------------------------------------------------|---------------------------|--------------------------|--------------------------------------|
| You were given an easier assignment? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were treated differently by people at work? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You felt supported by your employer? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You felt supported by your co-workers? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were transferred or moved? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You were forced into retirement? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |
| You chose to retire earlier than you had planned? | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not Applicable |

Work and Insurance continued

Do you currently have health insurance coverage?

☐ Yes ☐ No

Indicate the source of your health insurance (check all that apply).

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other (specify)

Other Insurance: Please describe

Do you have a life insurance policy?

☐ Yes ☐ No ☐ Unsure

During the time you were treated for melanoma, were you covered by health insurance for all or part of the time?

☐ Yes ☐ No

Indicate the source of your health insurance at the time you were treated for melanoma (check all that apply).

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other (specify)

Other Insurance: Please describe

Work and Insurance continued

After your melanoma diagnosis, did you experience any of the following problems with a health insurance plan related to your melanoma treatment?

Plan would not pay anything for care that you thought was covered ☐ Yes ☐ No

Plan paid less than you expected for a bill received from a doctor, hospital or lab ☐ Yes ☐ No

Reached a limit of what the insurance company would pay for cancer treatment ☐ Yes ☐ No

Turned away or unable to get specific type of treatment because of insurance issues ☐ Yes ☐ No

How much of a burden on your family were the costs of overall medical care related to your melanoma treatment?

☐ A major burden ☐ A minor burden ☐ Not a burden at all

How much distress did you experience from dealing with insurance and/or billing for your melanoma care? ☐ A lot ☐ Some ☐ Very little ☐ None

Did any of the following things happen to you as a result of the financial cost of dealing with melanoma?

Used up all or most of your savings ☐ Yes ☐ No ☐ Not Applicable

Unable to pay for basic necessities like food, heat, or housing ☐ Yes ☐ No

Borrowed money from relatives or friends ☐ Yes ☐ No

Borrowed money from other sources (such as bank loan, mortgage on your home, a retirement account) ☐ Yes ☐ No

Contacted by a collection agency ☐ Yes ☐ No

Work and Insurance continued

Did any of the following things happen to you as a result of the financial cost of dealing with melanoma?

Declared bankruptcy ☐ Yes ☐ No

Sought the aid of a charity or public assistance ☐ Yes ☐ No

Lost your health insurance ☐ Yes ☐ No ☐ Not Applicable

Couldn't buy health insurance because of having melanoma ☐ Yes ☐ No ☐ Not Applicable

Couldn't buy life insurance because of having melanoma ☐ Yes ☐ No ☐ Not Applicable

VII. Well-Being Associated with Melanoma Diagnosis

These next questions are about your emotional well-being after a melanoma diagnosis.

How difficult is it for you to cope today as a result of your melanoma diagnosis and treatment?

Not at all difficult Very difficult



(Place a mark on the scale above)

How good is your quality of life?

Extremely poor Excellent



(Place a mark on the scale above)

How much happiness do you feel?

None at all A great deal



(Place a mark on the scale above)

Do you feel like you are in control of things in your life?

Not at all Completely



(Place a mark on the scale above)

Well-Being after Melanoma continued

How satisfying is your life?

Not at all Completely*(Place a mark on the scale above)*

How is your present ability to concentrate or to remember things?

Extremely poor Excellent*(Place a mark on the scale above)*

How useful do you feel?

Not at all Extremely*(Place a mark on the scale above)*

Has your melanoma diagnosis or treatment caused changes in your appearance?

Not at all Extremely*(Place a mark on the scale above)*

Has your illness or treatment caused changes in your self-concept (the way you see yourself)?

Not at all Extremely*(Place a mark on the scale above)*

How serious do you consider melanoma to be?

Not at all Extremely*(Place a mark on the scale above)*

How distressing were the following aspects of your melanoma diagnosis and treatment?

Not at all Very

[illegible]

(Place a mark on the scale above)

Not at all Very

[illegible]

(Place a mark on the scale above)

Not at all Very

[illegible]

(Place a mark on the scale above)

Not at all A great deal

[illegible]

(Place a mark on the scale above)

Not at all A great deal

[illegible]

(Place a mark on the scale above)

Well-Being after Melanoma continued

To what extent are you fearful of:

Future diagnostic tests

No fear Extreme fear

(Place a mark on the scale above)

A second melanoma

No fear Extreme fear

(Place a mark on the scale above)

Recurrence of your melanoma

No fear Extreme fear

(Place a mark on the scale above)

Spreading (metastasis) of your melanoma

No fear Extreme fear

(Place a mark on the scale above)

Dying from melanoma

No fear Extreme fear

(Place a mark on the scale above)

Children/Other Family Members getting melanoma

No fear Extreme fear

(Place a mark on the scale above)

Well-Being after Melanoma continued

How much has your melanoma diagnosis affected your consideration of having children or having more children?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very Much
- ☐ Not Applicable

Well-Being after Melanoma continued

These next questions are about your social well-being.

How distressing has melanoma been for your family?

Not at all A great deal



(Place a mark on the scale above)

Is the amount of support you receive from others sufficient to meet your needs?

Not at all A great deal



(Place a mark on the scale above)

Is your continuing health care interfering with your personal relationships?

Not at all A great deal



(Place a mark on the scale above)

Is your sexuality impacted by your melanoma?

Not at all A great deal



(Place a mark on the scale above)

How comfortable are you talking with others about your melanoma?


Not at all comfortable Very comfortable




(Place a mark on the scale above)

Well-Being after Melanoma continued


To what degree has your melanoma and treatment interfered with your employment?

No problem Severe problem

(Place a mark on the scale above)


To what degree has your melanoma and treatment interfered with your activities at home?

No problem Severe problem

(Place a mark on the scale above)


How much isolation do you feel is caused by your melanoma or treatment?

Not at all A great deal

(Place a mark on the scale above)

How much financial burden have you incurred as a result of your melanoma and treatment?

Not at all A great deal

(Place a mark on the scale above)

How frustrated are you that some people do not understand the seriousness of a melanoma diagnosis?

Not at all A great deal

(Place a mark on the scale above)

Well-Being after Melanoma continued**Please tell us about the impact of a melanoma diagnosis on your life.**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Because of melanoma, I live each day one at a time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel grateful to be alive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like time in my life is limited.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I learned something about life because of having had melanoma.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having had melanoma makes me feel unsure about my future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about my future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am afraid to die.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Well-Being after Melanoma contiued

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I can accept my mortality, that I am going to die someday.	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like time in my life is running out.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having had melanoma has made me realize that time is precious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having had melanoma has strengthened my religious faith or my sense of spirituality.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I consider myself to be a cancer survivor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I spend more time with loved ones since my diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

VIII. Your Background

Please tell us about yourself.

What is your current age?

What is your sex?

☐ Male ☐ Female

What is your race? (1 or more categories may be selected)

- ☐ White
☐ Black or African American
☐ American Indian or Alaska Native
☐ Asian Indian
☐ Chinese
☐ Filipino
☐ Japanese
☐ Korean
☐ Vietnamese
☐ Other Asian
☐ Native Hawaiian
☐ Guamanian or Chamorro
☐ Samoan
☐ Other Pacific Islander
((check all that apply))

Are you Hispanic, Latino/a, or of Spanish origin? (1 or more categories may be selected)

- ☐ No, not of Hispanic, Latino/a, Spanish origin
☐ Yes, Mexican, Mexican American, Chicano/a
☐ Yes, Puerto Rican
☐ Yes, Cuban origin

Your Background continued

What is the highest level of schooling you have completed?

- ☐ Less than high school
- ☐ High school graduate
- ☐ Vocational or business school or AA degree
- ☐ Some college
- ☐ College or university graduate (bachelors degree)
- ☐ Graduate or professional training (graduate degree)

What is your marital status?

- ☐ Never married
- ☐ Married / Partnered
- ☐ Widowed
- ☐ Divorced

What is your annual household income?

- ☐ Less than \$20,000
- ☐ \$20,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ \$150,000 to \$199,999
- ☐ \$200,000 or more
- ☐ Prefer not to say

If you have any other comments for us about your experience with melanoma, please share them in the box provided.

Future Research

We are interested in conducting new research about melanoma that builds on the information that you have so generously shared with us. Below, we ask for your permission to continue to work with us on melanoma research. You may agree to none, one, two or all three of our requests. Thank you for your consideration!

1. Request to allow us to send you information on a new research project: We are asking for your permission to send you information on a new research project that involves collection of records related to your melanoma treatment and a sample of your melanoma tumor. If you agree, we will mail you additional information about the project and you can make a final decision at that time. If you mark 'yes', we will mail you additional information. You can make a final decision at that time.

- ☐ Yes, I would consider this, please send me the additional information.
☐ No. Please do not contact me in the future.

2. Request your permission to collect information from the State Cancer Registry: To learn more about the effect of melanoma on your current or future health, would you be willing to give us permission to get information about your cancer diagnosis (or diagnoses) that is contained in the state cancer registry?

- ☐ Yes, I give my permission.
☐ No, I prefer not to participate.

3. Request permission to contact you in the future: Would you give us permission to contact you in the future for new research projects? And if yes, could you provide the name of a contact person who will know of your whereabouts in the event that you move?

- ☐ Yes, I give my permission.
☐ No. Please do not contact me in the future.

My contact information:

E-Mail Address _____

Telephone Number _____

Alternative person you may contact:

Name _____

Relationship _____

Street Address _____

City _____

Zip Code _____

E-Mail Address _____

Telephone Number _____

You have completed the survey. Thank you very much for participating in our study.

Please click "submit" as the final step.

Appendix D. Online Control Survey

Skin Health Study - Follow-up Survey

Thank you for being willing to share your experience by completing our online survey.

For a better online experience, please use a computer rather than a tablet or smart phone.

Please use the Previous and Next buttons found at the bottom of each page instead of the back and forward arrows on your browser.

For each question, please give the answer that seems to best describe how you feel or what your experience has been like. Some of the survey questions may seem the same, but they are all important to answer.

The reset button can be used to clear your answer(s) if you want to start a question over.

If you do not finish in one sitting, you can close your browser window and come back later to where you left off. To do this:

- Click on Save and Return Later
- You will be given a code, or password, to use upon re-entry
- Use the same web link that was included in your letter for re-entry, click on Returning in the top right corner, then enter the code given

Study ID This number can be found on your letter.

Please Re-Enter Study ID

The Study ID's did not match. Please correct.

Date

((Please click on the 'Now' button))

CONSENT FORM**INTRODUCTION**

You are invited to be in a scientific research study that is being conducted by Dr. DeAnn Lazovich at the University of Minnesota School of Public Health. The purpose of this study is to learn more about the experiences of people with melanoma after diagnosis compared to people without a melanoma diagnosis. The study is funded by the University of Minnesota. You were selected because you previously participated in the Skin Health Study between 2004 and 2009.

STUDY PROCEDURES

If you choose to be in the study, we will ask you to take a one-time online survey. The survey asks about your current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. The survey will take between 15 and 25 minutes.

CONFIDENTIALITY

The records of this study will be kept private and confidential. In any report we might publish, we will not include any information that will make it possible to identify a participant. Every precaution is taken to make sure that all data are kept safe and secure. The online survey uses a secure web interface to protect the data that you enter. Only researchers involved in this project will have access to these data files.

RISKS AND BENEFITS

There are no known risks, except for possible breach of confidentiality. However we will take every precaution to keep your study information confidential. Although there are no direct benefits to you from participating in this study, the information you provide may help us learn about ways to assist persons who have been diagnosed with melanoma.

VOLUNTARY NATURE

Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

WHOM TO CONTACT

If you have any questions about the study, you may contact Dr. Lazovich or her research staff by email (shs@umn.edu) or by phone (612 624-3056). If you have questions or concerns regarding this study and would like to talk to someone other than the researcher (s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at Fairview Research Administration, 2433 Energy Park Drive, St. Paul, MN, 55108.

Statement of consent: Check the appropriate box below

- ☐ I have read and understood the above information. I agree to participate in this study.
☐ I do not agree to participate in the study.

I. Your Health Habits

The first questions are about your physical activity, diet, body size, sun protection, alcohol and smoking habits.

Physical Activity Habits

Consider a typical 7-day period (a week) in the past month.

How many times on average do you do the following kinds of exercise for more than 15 minutes during your free time and for how long per exercise session?

Strenuous activity (heart beats rapidly, heaving sweating)

Examples: running, jogging, hockey, soccer, squash, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling, vigorous aerobic dance classes, heavy weight training.

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Moderate activity (not exhausting, light sweating)

Examples: fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing.

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Mild activity (minimal effort, no sweating)

Examples: easy walking, yoga, archery, fishing, bowling, lawn bowling, shuffleboard, horseshoes, golf, snowmobiling

Times per week

(Enter times per week)

Average amount of time per session

(Enter minutes)

Diet Habits

How many days per week do you eat at least five (5) servings of fruits and vegetables a day? One serving = 1 piece of fruit, half a cup of cooked vegetables, or one cup of raw leafy vegetables.

- ☐ 0 days
- ☐ 1 day
- ☐ 2 days
- ☐ 3 days
- ☐ 4 days
- ☐ 5 days
- ☐ 6 days
- ☐ 7 days

Do you currently take a multi-vitamin?

- ☐ Yes
- ☐ No

On average, how many days per week do you take a multi-vitamin?

- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

Do you currently take vitamin D on a regular basis, either as part of a multi-vitamin, calcium supplement, or as its own pill?

- ☐ Yes
- ☐ No
- ☐ Don't know

On average, how many days per week do you take vitamin D?

- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

What is the usual amount you take each day?

- ☐ Less than 400 IU
- ☐ 400 IU
- ☐ 600 IU
- ☐ 800 IU
- ☐ 1000 IU
- ☐ 2000 IU
- ☐ Greater than 2000 IU
- ☐ Other
- ☐ Unknown

Usual Amount

Body Size

How tall are you?

Feet

(Feet)

Inches

(Inches)

What is your current weight in pounds?

(Pounds)

Sun Habits

In the summer, on average, how many hours are you outside per day between 10 am and 4 pm...

on WEEKDAYS (Monday - Friday)?

- ☐ 0 to 30 minutes
- ☐ 31 minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

on WEEKEND DAYS (Saturday & Sunday)?

- ☐ 0 to 30 minutes
- ☐ 31 minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

In the past 12 months, how many times did you have a red OR painful sunburn that lasted a day or more?

- ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

Sun Habits continued

For the following questions, think about what you typically do when you are outside during the summer on a warm sunny day.

When you are outside during the summer on a warm sunny day, how often do you wear sunscreen ?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you wear a shirt with sleeves that cover your shoulders?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you wear a hat with a wide brim?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you stay in the shade or under an umbrella?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

When you are outside during the summer on a warm sunny day, how often do you spend time in the sun in order to get a tan?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

Sun Habits continued

In the last 12 months, have you used a tanning bed or booth with tanning lamps?

☐ Yes ☐ No

How many times in the last 12 months have you used a tanning bed or booth with tanning lamps?

In the last 12 months, have you had your skin checked from head to toe by a health professional?

☐ Yes ☐ No

In the last 12 months have you or a partner examined your entire body, including your back for skin cancer?

☐ Yes ☐ No

How many times?

What is the color of your untanned skin?

☐ Very fair ☐ Fair ☐ Olive
☐ Light brown ☐ Dark brown
☐ Very dark

Alcohol Habits

During the past 30 days, how many days per month did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage or liquor? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine or a drink with one shot of liquor.

- ☐ none
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10
☐ 11
☐ 12
☐ 13
☐ 14
☐ 15
☐ 16
☐ 17
☐ 18
☐ 19
☐ 20
☐ 21
☐ 22
☐ 23
☐ 24
☐ 25
☐ 26
☐ 27
☐ 28
☐ 29
☐ 30
(days per month)

During the past 30 days, on the days when you drank, about how many drinks did you drink on the average?

- ☐ 1 drink
☐ 2 drinks
☐ 3 drinks
☐ 4 drinks
☐ 5 drinks
☐ 6 drinks
☐ 7 drinks
☐ 8 drinks
☐ 9 drinks
☐ 10 drinks
☐ 11 drinks
☐ 12 drinks
☐ more than 12

Considering all types of alcoholic beverages, how many times during the past 30 days did you have... 5 or more drinks on one occasion if you are a man? 4 or more drinks on one occasion if you are a woman?

(times)

Smoking Habits

Do you currently smoke cigarettes on a regular basis?

☐ Yes ☐ No

On average, how many packs of cigarettes do you smoke per day now? (1 pack = 20 cigarettes)

- ☐ Less than ½ pack
☐ ½ pack
☐ 1 pack
☐ 1 ½ packs
☐ 2 packs
☐ more than 2 packs

Do you currently use any of the following tobacco products on a regular basis? Mark all that apply. Mark "none" if you do not use any on a regular basis.

- ☐ None
☐ Cigars
☐ Pipe tobacco
☐ Chewing tobacco
☐ Dip or snuff
☐ Other (please specify)

If Other, please describe

II. Your Health and Well-Being

The next questions ask about your general physical, emotional and social well-being.

In general, would you say your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

Compared to one year ago, how would you rate your health in general now?

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

Your Health and Well-Being continued

The following questions are about activities that you might do during a typical day. Does your health now limit in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	Not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than a mile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did work or other activities less carefully than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

How much bodily pain have you had during the past 4 weeks?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

Your Health and Well-Being continued These next few questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Health and Well-Being continued

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

Your Health and Well-Being continued**How TRUE or FALSE is each of the following statements for you?**

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Emotional Well-Being

The next set of questions will ask you about your emotional well-being.

I feel tense or 'wound up':

- ☐ Most of the time ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all

I still enjoy the things I used to enjoy:

- ☐ Definitely as much ☐ Not quite as much ☐ Only a little ☐ Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly ☐ Yes, but not too badly ☐ A little, but it doesn't worry me
☐ Not at all

I can laugh and see the funny side of things:

- ☐ As much as I always could ☐ Not quite so much now ☐ Definitely not so much now
☐ Not at all

Worry thoughts go through my mind:

- ☐ A great deal of the time ☐ A lot of the time ☐ From time to time, but not too often
☐ Only occasionally

Emotional Well-Being continued

I feel cheerful:

- ☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

I can sit at ease and feel relaxed:

- ☐ Definitely ☐ Usually ☐ Not often ☐ Not at all

I feel restless as if I have to be on the move:

- ☐ Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all

I look forward with enjoyment to things:

- ☐ As much as I ever did ☐ Rather less than I used to ☐ Definitely less than I used to
☐ Hardly at all

I get sudden feelings of panic:

- ☐ Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all

Emotional Well-Being continued

I can enjoy a good book or radio or TV program:

- ☐ Often ☐ Sometimes ☐ Not often ☐ Very seldom

I feel as if I am slowed down:

- ☐ Nearly all the time ☐ Very often ☐ Sometimes ☐ Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

I have lost interest in my appearance:

- ☐ Definitely
☐ I don't take as much care as I should
☐ I may not take quite as much care
☐ I take just as much care as ever

III. Health Conditions

Has a medical doctor or healthcare professional ever told you that you have any of the following?

Heart Problems, such as a heart attack, coronary artery disease, congestive heart failure, irregular heartbeat, etc. ☐ Yes ☐ No

Hypertension (high blood pressure) ☐ Yes ☐ No

Chronic back pain, including sciatica (pain or numbness that travels down your leg to below your knees) ☐ Yes ☐ No

Arthritis ☐ Yes ☐ No

Stroke, including mini-stroke or blood clots in the brain ☐ Yes ☐ No

Severe problems with memory or concentration ☐ Yes ☐ No

Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease) ☐ Yes ☐ No

Stomach and/or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease ☐ Yes ☐ No

Health Conditions continued

Has a medical doctor or healthcare professional ever told you that you have any of the following?

Diabetes, high blood sugar, or sugar in urine ☐ Yes ☐ No

Depression (feeling sad or blue) that resulted in treatment with medication and/or counseling ☐ Yes ☐ No

Anxiety or "nervousness" that resulted in treatment with medication and/or counseling ☐ Yes ☐ No

Neuropathy (numbness in both hands or both feet) ☐ Yes ☐ No

Melanoma ☐ Yes ☐ No

Cancer other than melanoma ☐ Yes ☐ No

Please describe _____

Other health condition(s) ☐ Yes ☐ No

Please describe _____

Health Conditions continued

Have any of the following members of your family been diagnosed with melanoma?

- | | | | |
|---------------|---------------------------|--------------------------|--------------------------------------|
| Parents | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Grandparents | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Brothers | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Sisters | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Children | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |
| Grandchildren | <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Not applicable |

VI. Work and Insurance

The next questions are about work and insurance.

What is your CURRENT employment status? If more than one category applies, please choose the one that best describes your current employment status.

- ☐ Paid full-time employment
- ☐ Paid part-time employment
- ☐ Self-employed
- ☐ Volunteer
- ☐ Homemaker
- ☐ Unemployed, looking for work
- ☐ Unemployed, not looking for work
- ☐ Not employed - disabled
- ☐ Retired, not working
- ☐ Student, not working

During the past 12 months, about how many days did you miss work at your job or business because of illness (do not include maternity leave)?

(days)

During the past 12 months, about how many days did illness keep you in bed more than half of the day (include days while an overnight patient in a hospital)?

(days)

Work and Insurance continued

Do you currently have health insurance coverage?

☐ Yes ☐ No

Indicate the source of your health insurance (check all that apply).

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other (specify)

Other Insurance: Please describe

Do you have a life insurance policy?

☐ Yes ☐ No ☐ Unsure

VIII. Your Background

Please tell us about yourself.

What is your current age?

☐ Male ☐ Female

What is your sex?

What is your race? (1 or more categories may be selected)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian Indian
- ☐ Chinese
- ☐ Filipino
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese
- ☐ Other Asian
- ☐ Native Hawaiian
- ☐ Guamanian or Chamorro
- ☐ Samoan
- ☐ Other Pacific Islander
- ((check all that apply))

Are you Hispanic, Latino/a, or of Spanish origin? (1 or more categories may be selected)

- ☐ No, not of Hispanic, Latino/a, Spanish origin
- ☐ Yes, Mexican, Mexican American, Chicano/a
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban origin

Your Background continued

What is the highest level of schooling you have completed?

- ☐ Less than high school
- ☐ High school graduate
- ☐ Vocational or business school or AA degree
- ☐ Some college
- ☐ College or university graduate (bachelors degree)
- ☐ Graduate or professional training (graduate degree)

What is your marital status?

- ☐ Never married
- ☐ Married / Partnered
- ☐ Widowed
- ☐ Divorced

What is your annual household income?

- ☐ Less than \$20,000
- ☐ \$20,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ \$150,000 to \$199,999
- ☐ \$200,000 or more
- ☐ Prefer not to say

Future Research

Request permission to contact you in the future: Would you give us permission to contact you in the future for new research projects? And if yes, could you provide the name of a contact person who will know of your whereabouts in the event that you move?

- ☐ Yes, I give my permission.
☐ No. Please do not contact me in the future.

My contact information:

E-Mail Address _____

Telephone Number _____

Alternative person you may contact:

Name _____

Relationship _____

Street Address _____

City _____

Zip Code _____

E-Mail Address _____

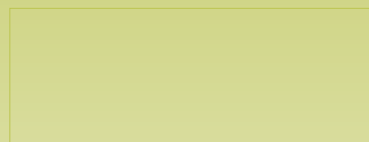
Telephone Number _____

You have completed the survey. Thank you very much for participating in our study.

Please click "submit" as the final step.

Skin Health Study: **Follow-up Survey**

Survey available online: <http://z.umn.edu/shs1>



Instructions

For each question, please give the answer that seems to best describe how you feel or what your experience has been like. Some of the survey questions may seem the same, but they are all important to answer.

There are questions on both the front and back of each page. Please answer all questions.



UNIVERSITY OF MINNESOTA

I. Your Health Habits

The first questions are about your physical activity, diet, body size, sun protection, and alcohol and smoking habits.

1. Consider a typical 7-day period (a week) in the past month. How many times on average do you do the following kinds of exercise for more than 15 minutes during your free time and for how long per exercise session?

a. **Strenuous activity** (heart beats rapidly, heaving sweating)

Examples: running, jogging, hockey, soccer, squash, cross country, skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling, vigorous aerobic dance classes, heavy weight training

Times per week: _____

Average amount of time per session (minutes): _____

b. **Moderate activity** (not exhausting, light sweating)

Examples: fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing

Times per week: _____

Average amount of time per session (minutes): _____

c. **Mild activity** (minimal effort, no sweating)

Examples: easy walking, yoga, archery, fishing, bowling, lawn bowling, shuffleboard, horseshoes, golf, snowmobiling

Times per week: _____

Average amount of time per session (minutes): _____

Diet Habits

2. How many days per week do you eat at least five (5) servings of fruit and vegetables a day?

One serving = 1 piece of fruit, half a cup of cooked vegetables or one cup of raw leafy vegetables.

- | | |
|---------------------------------|---------------------------------|
| <input type="checkbox"/> 0 days | <input type="checkbox"/> 4 days |
| <input type="checkbox"/> 1 day | <input type="checkbox"/> 5 days |
| <input type="checkbox"/> 2 days | <input type="checkbox"/> 6 days |
| <input type="checkbox"/> 3 days | <input type="checkbox"/> 7 days |

3. Do you currently take a multi-vitamin?

- ☐ No
- ☐ Yes → **3a. On average, how many days per week do you take a multi-vitamin?**
- | |
|-----------------------------------|
| <input type="checkbox"/> 1-2 days |
| <input type="checkbox"/> 3-4 days |
| <input type="checkbox"/> 5-6 days |
| <input type="checkbox"/> 7 days |

4. Do you currently take vitamin D on a regular basis, either as part of a multi-vitamin, calcium supplement, or as its own pill?

- ☐ No
- ☐ Yes → **4a. On average, how many days per week do you take vitamin D?**
- | |
|-----------------------------------|
| <input type="checkbox"/> 1-2 days |
| <input type="checkbox"/> 3-4 days |
| <input type="checkbox"/> 5-6 days |
| <input type="checkbox"/> 7 days |

4b. What is the usual amount you take each day?

- | |
|--------------------------------------------|
| <input type="checkbox"/> Less than 400 IU |
| <input type="checkbox"/> 400 IU |
| <input type="checkbox"/> 600 IU |
| <input type="checkbox"/> 800 IU |
| <input type="checkbox"/> 1000 IU |
| <input type="checkbox"/> 2000 IU |
| <input type="checkbox"/> More than 2000 IU |
| <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Unknown |

5. How tall are you?

_____ Feet _____ Inches

6. What is your current weight in pounds? _____

Sun Habits

7. In the summer, on average, how many hours are you outside per day between 10am and 4pm...

a. On WEEKDAYS (Monday – Friday)?

- ☐ 0-30 minutes
- ☐ 31-minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

b. On WEEKEND DAYS (Saturday & Sunday)?

- ☐ 0-30 minutes
- ☐ 31-minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

8. In the past 12 months, how many times did you have a red OR painful sunburn that lasted a day or more?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more

9. For the following questions, think about what you typically do when you are outside during the summer on a warm sunny day:

<i>When you are outside during the summer on a warm sunny day, how often do...</i>	Never	Rarely	Sometimes	Often	Always
a. Wear sunscreen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Wear a shirt with sleeves that cover your shoulders?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Wear a hat with a wide brim?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Stay in the shade or under an umbrella?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Spend time in the sun in order to get a tan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. In the last 12 months, have you used a tanning bed or booth with tanning lamps?

☐ No

☐ Yes → 10a. How many times in the last 12 months have you used a tanning bed or booth with tanning lamps? _____

11. In the last 12 months, have you had your skin checked from head to toe by a health professional?

☐ No

☐ Yes

12. In the last 12 months have you or your partner examined your entire body, including your back, for skin cancer?

☐ No

☐ Yes → 12a. How many times in the past 12 months? _____

13. What is the color of your untanned skin?

☐ Very fair

☐ Fair

☐ Olive

☐ Light brown

☐ Dark brown

☐ Very dark

14. Since your melanoma diagnosis, have you been...

	More	Same	Less	Never my habit
a. Avoiding exposure to the sun?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Wearing sun-protective clothing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Using sunscreen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Alcohol Habits

15. During the past 30 days, how many days per month did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage or liquor? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine or a drink with one shot of liquor.

_____ (number of days in past month: 0-30)

16. During the past 30 days, on the days when you drank, about how many drinks did you drink on average?

_____ (number of drinks)

17. Considering all types of alcoholic beverages, how many times during the past 30 days did you have...

... 5 or more drinks on one occasion if you are a man?

... 4 or more drinks on one occasion if you are a woman?

_____ (times in past 30 days)

Smoking Habits

18. Do you currently smoke cigarettes on a regular basis?

☐ No

☐ Yes → 18a. On average, how many packs of cigarettes do you smoke per day?

(1 pack = 20 cigarettes)

☐ Less than ½ pack

☐ ½ pack

☐ 1 pack

☐ 1½ packs

☐ 2 packs

☐ More than 2 packs

19. Do you currently use any of the following tobacco products on a regular basis? Mark all that apply. Mark "none" if you do not use any on a regular basis.

☐ None

☐ Cigars

☐ Pipe tobacco

☐ Chewing tobacco

☐ Dip or snuff

☐ Other → Specify: _____

II. Your Health Habits and Well-Being

The next questions ask about your general physical, emotional, and social well-being.

20. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

21. Compared to 1 year ago, how would you rate your health in general now?

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

22. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	Not limited at all
a. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Climbing <u>several</u> flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Climbing <u>one</u> flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Walking <u>more than a mile</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Walking <u>several blocks</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Walking <u>one block</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your *physical health*?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of *any emotional problems* (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Did work or other activities <u>less carefully than usual</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

26. How much bodily pain have you had in the past 4 weeks?

- ☐ None
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

27. During the past 4 weeks, how much did pain interfere with your normal work (Including work outside the house and housework)?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

28. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you been very nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Have you felt downhearted and depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Have you been happy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

30. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Emotional Well-Being

The next set of questions will ask you about your emotional well-being.

31. I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

32. I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite as much
- ☐ Only a little
- ☐ Hardly at all

33. I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

34. I can laugh and see the funny side of things:

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

35. Worry thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

36. I feel cheerful:

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

37. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

38. I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

39. I look forward with enjoyment to things:

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

40. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

41. I can enjoy a good book or radio or TV program:

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

42. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

43. I get a sort of frightened feeling like ‘butterflies’ in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

44. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

III. Health Conditions

45. Has a medical doctor or healthcare professional ever told you that you have any of the following?

	Yes	No
a. Heart problems, such as a heart attack, coronary artery disease, congestive heart failure, irregular heartbeat, etc.	<input type="checkbox"/>	<input type="checkbox"/>
b. Hypertension (high blood pressure)	<input type="checkbox"/>	<input type="checkbox"/>
c. Chronic back pain, including sciatica (pain or numbness that travels down your leg to below your knees)	<input type="checkbox"/>	<input type="checkbox"/>
d. Arthritis	<input type="checkbox"/>	<input type="checkbox"/>
e. Stroke, including mini-stroke or blood clots in the brain	<input type="checkbox"/>	<input type="checkbox"/>
f. Severe problems with memory or concentration	<input type="checkbox"/>	<input type="checkbox"/>
g. Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease)	<input type="checkbox"/>	<input type="checkbox"/>
h. Stomach and/or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease	<input type="checkbox"/>	<input type="checkbox"/>
i. Diabetes, high blood sugar, or sugar in urine	<input type="checkbox"/>	<input type="checkbox"/>
j. Depression (feeling sad or blue) that resulted in treatment with medication and/or counseling	<input type="checkbox"/>	<input type="checkbox"/>
k. Anxiety or “nervousness” that resulted in treatment with medication and/or counseling	<input type="checkbox"/>	<input type="checkbox"/>
l. Neuropathy (numbness in both hands or both feet)	<input type="checkbox"/>	<input type="checkbox"/>
m. Cancer other than melanoma <i>If yes, provide details:</i>	<input type="checkbox"/>	<input type="checkbox"/>
n. Other health conditions <i>If yes, provide details:</i>	<input type="checkbox"/>	<input type="checkbox"/>

46. Have any of the following members of your family been diagnosed with melanoma?

	Yes	No	Not Applicable
a. Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Brother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Grandchildren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IV. Cancer Experience

The next questions are about your experience after diagnosis with your FIRST (or only) melanoma.

47. What year were you first diagnosed with melanoma? _____

48. Where on your body was your melanoma found?

- ☐ Head or neck
- ☐ Trunk
- ☐ Arms
- ☐ Legs

49. What stage was your melanoma?

- ☐ Stage I
- ☐ Stage II
- ☐ Stage III
- ☐ Stage IV
- ☐ Don't know

50. Please mark all treatments you received when your melanoma was first diagnosed:

	Yes	No	Don't Know
a. Surgery to remove melanoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Surgery to remove lymph nodes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. A skin graft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Radiation treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Immunotherapy (such as Interferon, vaccines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

51. Has your doctor ever told you that your melanoma has come back to the same part of your body (recurrence)?

☐ No

☐ Yes → 51a. What year was the recurrence? _____

52. Has your doctor ever told you that your melanoma has spread to another part of your body (metastasized)?

☐ No

☐ Yes → 52a. What year did the melanoma spread? _____

If you answered “No” to both questions 51 & 52 above, skip to question 54 on page 14. Otherwise continue below.

53. If your first melanoma returned or spread to another part of your body, please mark all additional treatments you have received:

	Yes	No	Don't Know
a. Surgery to remove melanoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Surgery to remove lymph nodes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. A skin graft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Radiation treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Immunotherapy (such as Interferon, vaccines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you had surgery to remove lymph nodes, continue below with question 54. Otherwise Skip to question 59 on page 16.

54. When you had surgery to remove lymph nodes, how many were removed?

- ☐ 1-4
- ☐ 5-9
- ☐ 10-14
- ☐ 15+
- ☐ Don't Know

55. Did you experience swelling or lymphedema lasting greater than 1 month at any point after surgery or radiation treatment?

- ☐ No → ***Skip to question 59 on page 16***
- ☐ Yes → ***Continue below***

55a. When did your swelling or lymphedema FIRST occur?

- ☐ Following treatment of your first melanoma
- ☐ Following treatment of melanoma that returned to same part of your body
- ☐ Following treatment of melanoma that spread to other parts of your body

55b. How long did the swelling last? (years/months) _____

55c. Where on your body was the swelling? _____

55d. Have you received or are you currently receiving treatment to PREVENT swelling or lymphedema following your surgery or radiation treatment?

- ☐ No → ***Skip to question 56 on page 16***
- ☐ Yes → ***Continue below***

55e. When did you first begin treatment to prevent swelling or lymphedema?

- ☐ Following treatment of your first melanoma
- ☐ Following treatment of melanoma that returned to same part of your body
- ☐ Following treatment of melanoma that spread to other parts of your body

55f. How long did you or have the treatments lasted? (years/months) _____

55g. What part of your body was treated? _____

If you have ever experienced swelling following surgery or radiation, continue below. Otherwise Skip to question 59 on page 16.

56. Do you still have swelling?

- ☐ No → ***Skip to question 59 on page 16***
☐ Yes → ***Continue below***

57. These questions are about the swelling that you have:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I am bothered by the amount of swelling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Movement of my swollen area is painful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Swelling keeps me from doing the things I want to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Swelling keeps me from wearing clothes or shoes I want to wear.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

58. Have you received or are you currently receiving treatment for your swelling or lymphedema?

- ☐ No → ***Skip to question 59 on page 16***
☐ Yes → ***Continue below***

58a. What types of treatment for swelling or lymphedema have you received? Check all that apply.

- ☐ Manual lymphatic drainage
☐ Compression
☐ Pump
☐ Exercise
☐ Other: _____

58b. How helpful have the treatments been for preventing swelling or lymphedema?

- ☐ Very helpful
☐ Somewhat helpful
☐ A little helpful
☐ Not at all helpful

59. Please describe how much these concerns affect you.

	Not at all	A little bit	Some what	Quite a bit	Very much
a. I feel numbness at my surgical site.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I have good range of movement in my arms and legs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am more aware of physical problems or changes in my body since having had melanoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. New symptoms, aches, pains, getting sick, make me worry about the melanoma coming back.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I am worried that family members may also develop skin cancer/melanoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I feel bothered by people's questions related to my melanoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am worried about the size of the scar.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I think about how my melanoma scar affects my attractiveness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I think about how noticeable the scar is to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I sometimes wear clothing to cover up my scar.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

V. Experience with Health Care System

These questions ask about your experience with the health care professionals who took care of you at the time you were first diagnosed with melanoma.

60. When you were first diagnosed with melanoma...

	Yes	No	Don't Know
Did the doctor tell you what the likely outcome of having melanoma would be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the doctor say the melanoma could be cured or go into long-term remission?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did the doctor say the melanoma was likely to be fatal or lead to death?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

61. When you first found out you had melanoma, were you mostly optimistic or mostly pessimistic about surviving melanoma?

- ☐ Mostly optimistic
- ☐ Mostly pessimistic
- ☐ Don't know

62. Before your diagnosis, how much did you know about melanoma?

- ☐ Nothing
- ☐ Very little
- ☐ Some
- ☐ Quite a bit
- ☐ A lot

63. Please rate the doctors and health professionals seen during the course of your treatment.

	Excellent	Good	Fair	Poor
a. Knowledge and expertise in handling your medical issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Level of compassion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Attention to factors outside of direct medical care, such as support network for dealing melanoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

64. During the course of your first melanoma treatment, did you receive conflicting information about melanoma from different doctors or health care professionals?

- ☐ Yes
- ☐ No
- ☐ Don't know

65. When getting care for your melanoma, was there ever a time when...

	Yes	No	Not Applicable
a. Your medical records or test results did not reach your doctor's office in time for your appointment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. You were sent for duplicate tests or diagnostic procedures by different doctors, nurses, or health care workers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You left a doctor's office without getting important questions answered about your care or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You were confused about the medication the doctor prescribed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. You had to wait longer than you thought you should to find out results of medical tests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

66. Did waiting for test results produce stress and anxiety?

- ☐ Yes, a lot
- ☐ Just some
- ☐ No

67. Did you ever have to make a decision about whether to undergo a treatment that would increase your chances of survival by only a small amount but could potentially lead to severe side effects?

- ☐ No → **Skip to question 68 on page 19**
- ☐ Yes → **Continue below**

67a. Did you decide to undergo the treatment?

- ☐ No
- ☐ Yes

67b. How satisfied are you with your decision?

- ☐ Not at all
- ☐ Somewhat
- ☐ Very much
- ☐ A little bit
- ☐ Quite a bit

VI. Work and Insurance

The next questions are about work and insurance.

68. What is your **CURRENT** employment status? If more than one category applies, please choose the one that best describes your current employment status.

- | | |
|----------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Paid full-time employment | <input type="checkbox"/> Unemployed, looking for work |
| <input type="checkbox"/> Paid part-time employment | <input type="checkbox"/> Unemployed, not looking for work |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Not employed – disabled |
| <input type="checkbox"/> Volunteer | <input type="checkbox"/> Retired, not working |
| <input type="checkbox"/> Homemaker | <input type="checkbox"/> Student, not working |

69. During the past 12 months, about how many days did you miss work at your job or business because of illness (do not include maternity leave)? _____ days

70. During the past 12 months, about how many days did illness keep you in bed more than half of the day (include days while an overnight patient in a hospital)? _____ days

71. At the time you were **FIRST DIAGNOSED** with melanoma, what was your employment status? If more than one category applies, please choose the one that best describes employment status when you were first diagnosed.

- | | |
|----------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Paid full-time employment | <input type="checkbox"/> Unemployed, looking for work |
| <input type="checkbox"/> Paid part-time employment | <input type="checkbox"/> Unemployed, not looking for work |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Not employed – disabled |
| <input type="checkbox"/> Volunteer | <input type="checkbox"/> Retired, not working |
| <input type="checkbox"/> Homemaker | <input type="checkbox"/> Student, not working |

72. At the time you were diagnosed with melanoma, were you offered the following benefits from your main employer? (or yourself if self-employed)

	Yes	No	Not Applicable
a. Paid sick time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Paid vacation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Unpaid time off	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Short-term disability coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Long-term disability coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

73. Since being diagnosed with melanoma, did you miss any days from work because of your melanoma (either for treatment, rest, side effect of treatment)?

- ☐ No → **Go to question 74**
☐ Yes → **Continue below**

73a. Approximately how many days did you miss? _____ days

74. How well did your employer treat you during your experience with melanoma?

- ☐ Very well
☐ Somewhat well
☐ Not too well
☐ Not well at all
☐ Not Applicable

75. Have any of the following things happened to you since you were diagnosed with melanoma?

	Yes	No	Not Applicable
a. You were laid off or fired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Your responsibilities on the job were cut?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You were passed over for a raise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You were passed over for a promotion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Your salary was reduced?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. You were demoted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. You were given an easier assignment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. You were treated differently by people at work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. You felt supported by your employer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. You felt supported by your co-workers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. You were transferred or moved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. You were forced into retirement?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. You chose to retire earlier than you had planned?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

76. Do you currently have health insurance coverage?

- ☐ No → **Go to question 77**
- ☐ Yes → **Continue below**

76a. Indicate the source of your health insurance (check all that apply)

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other: _____

77. Do you have a life insurance policy?

- ☐ Yes
- ☐ No
- ☐ Unsure

78. During the time you were treated for melanoma, were you covered by health insurance for all or part of the time?

- ☐ No → **Go to question 80 on page 22**
- ☐ Yes → **Continue below**

78a. Indicate the source of your health insurance at the time you were treated for melanoma (check all that apply)

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other: _____

79. After your melanoma diagnosis, did you experience any of the following problems with a health insurance plan related to your melanoma treatment?

	Yes	No
a. Plan would not pay anything for care that you thought was covered	<input type="checkbox"/>	<input type="checkbox"/>
b. Plan paid less than you expected for a bill received from a doctor, hospital or lab	<input type="checkbox"/>	<input type="checkbox"/>
c. Reached a limit of what the insurance company would pay for cancer treatment	<input type="checkbox"/>	<input type="checkbox"/>
d. Turned away or unable to get specific type of treatment because of insurance issues	<input type="checkbox"/>	<input type="checkbox"/>

80. How much of a burden on your family were the costs of overall medical care related to your melanoma treatment?

- ☐ A major burden
- ☐ A minor burden
- ☐ Not a burden at all

81. How much distress did you experience from dealing with insurance and/or billing for your melanoma care?

- ☐ A lot
- ☐ Some
- ☐ Very little
- ☐ None

82. Did any of the following things happen to you as a result of the financial cost of dealing with melanoma?

	Yes	No	Not Applicable
a. Used up all or most of your savings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Unable to pay for basic necessities like food, heat or housing	<input type="checkbox"/>	<input type="checkbox"/>	
c. Borrowed money from relatives or friends	<input type="checkbox"/>	<input type="checkbox"/>	
d. Borrowed money from other sources (such as a bank loan, mortgage on your home, a retirement account)	<input type="checkbox"/>	<input type="checkbox"/>	
e. Contacted by a collection agency	<input type="checkbox"/>	<input type="checkbox"/>	
f. Declared bankruptcy	<input type="checkbox"/>	<input type="checkbox"/>	
g. Sought the aid of a charity or public assistance	<input type="checkbox"/>	<input type="checkbox"/>	
h. Lost your health insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Couldn't buy health insurance because of having melanoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Couldn't buy life insurance because of having melanoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VII. Well-Being Associated with Melanoma Diagnosis

Circle the number that best describes you for each question.

EXAMPLE: How good is your quality of life?

Extremely poor 0 10 20 30 40 50 60 70 **80** 90 100 *Excellent*

83. How difficult is it for you to cope today as a result of your melanoma diagnosis and treatment?

Not at all difficult 0 10 20 30 40 50 60 70 80 90 100 *Very Difficult*

84. How good is your quality of life?

Extremely poor 0 10 20 30 40 50 60 70 80 90 100 *Excellent*

85. How much happiness do you feel?

None at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

86. Do you feel like you are in control of things in your life?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Completely*

87. How satisfying is your life?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Completely*

88. How is your present ability to concentrate or to remember things?

Extremely poor 0 10 20 30 40 50 60 70 80 90 100 *Excellent*

89. How useful do you feel?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Extremely*

90. Has your melanoma diagnosis or treatment caused changes in your appearance?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Extremely*

91. Has your illness or treatment caused changes in your self-concept (the way you see yourself)?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Extremely*

92. How serious do you consider melanoma to be?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Extremely*

93. How distressing were the following aspects of your melanoma diagnosis and treatment?

a. Initial diagnosis

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very*

b. Melanoma treatments

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very*

c. Time since your treatment was completed

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very*

d. How much anxiety do you have?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very*

e. How much depression do you have?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very*

94. To what extent are you fearful of:

a. Future diagnostic tests

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

b. A second melanoma

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

c. Recurrence of your melanoma

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

d. Spreading (metastasis) of your melanoma

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

e. Dying from melanoma

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

f. Children/Other family members getting melanoma

No fear 0 10 20 30 40 50 60 70 80 90 100 *Extreme fear*

95. How much has your melanoma diagnosis affected your consideration of having children or having more children?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much
- ☐ Not Applicable

These next questions are about your social well-being.

96. How distressing has melanoma been for your family?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

97. Is the amount of support you receive from others sufficient to meet your needs?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

98. Is your continuing health care interfering with your personal relationships?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

99. Is your sexuality impacted by your melanoma?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

100. How comfortable are you talking with others about your melanoma?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *Very comfortable*
comfortable

101. To what degree has your melanoma and treatment interfered with your employment?

No problem 0 10 20 30 40 50 60 70 80 90 100 *Severe problem*

102. To what degree has your melanoma and treatment interfered with your activities at home?

No problem 0 10 20 30 40 50 60 70 80 90 100 *Severe problem*

103. How much isolation do you feel is caused by your melanoma or treatment?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

104. How much financial burden have you incurred as a result of your melanoma and treatment?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

105. How frustrated are you that some people do not understand the seriousness of a melanoma diagnosis?

Not at all 0 10 20 30 40 50 60 70 80 90 100 *A great deal*

106. Please tell us about the impact of a melanoma diagnosis on your life.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. Because of melanoma, I live each day one at a time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I feel grateful to be alive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I feel like time in my life is limited.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I learned something about life because of having had melanoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Having had melanoma makes me feel unsure about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I worry about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am afraid to die.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I can accept my mortality, that I am going to die someday.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I feel like time in my life is running out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Having had melanoma has made me realize that time is precious.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Having had melanoma has strengthened my religious faith or my sense of spirituality.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. I consider myself to be a cancer survivor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. I spend more time with loved ones since my diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VIII. Your Background

107. What is your current age? _____

108. What is your sex?

- ☐ Male
☐ Female

109. What is your race? (1 or more categories may be selected)

- | | |
|-----------------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> White | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Other Asian |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Native Hawaiian |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Guamanian or Chamorro |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Japanese | <input type="checkbox"/> Other Pacific Islander |

110. Are you Hispanic, Latino/a, or of Spanish origin? (1 or more categories may be selected)

- ☐ No, not of Hispanic, Latino/a, Spanish origin
- ☐ Yes, Mexican, Mexican American, Chicano/a
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban origin

111. What is the highest level of schooling you have completed?

- ☐ Less than high school
- ☐ High school graduate
- ☐ Vocational or business school or AA degree
- ☐ Some college
- ☐ College or university graduate (bachelor's degree)
- ☐ Graduate or professional training (graduate degree)

112. What is your marital status?

- | | |
|----------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Never married | <input type="checkbox"/> Widowed |
| <input type="checkbox"/> Married / Partnered | <input type="checkbox"/> Divorced |

113. What is your annual household income?

- | | |
|-----------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$100,000 to \$149,999 |
| <input type="checkbox"/> \$20,000 to \$49,999 | <input type="checkbox"/> \$150,000 to \$199,999 |
| <input type="checkbox"/> \$50,000 to \$74,999 | <input type="checkbox"/> \$200,00 or more |
| <input type="checkbox"/> \$75,000 to \$99,999 | <input type="checkbox"/> Prefer not to say |

*** CONTINUE TO BACK PAGE ***

Future research

We are interested in conducting new research about melanoma that builds on the information that you have so generously shared with us. Below, we ask for your permission to continue to work with us on melanoma research. You may agree to none, one, two or all three of our requests. Thank you for your consideration!

1. Request to allow us to send you information on a new research project:

We are asking for your permission to send you information on a new research project that involves collection of records related to your melanoma treatment and a sample of your melanoma tumor. If you agree, we will mail you additional information about the project and you can make a final decision at that time.

☐ **Yes, I would consider this, please send me the additional information.**

☐ **No, I prefer not to participate.**

2. Request your permission to collect information from the State Cancer Registry:

To learn more about the effect of melanoma on your current or future health, would you be willing to give us permission to get information about your cancer diagnosis (or diagnoses) that is contained in the state cancer registry?

☐ **Yes, I give my permission.**

☐ **No, I prefer not to participate.**

3. Request permission to contact you in the future:

Would you give us permission to contact you in the future for new research projects? If yes, could you provide the name of a contact person who will know of your whereabouts in the event that you move?

☐ **Yes, I give my permission.**

My contact Information:

Email address: _____ Telephone Number: _____

Alternative Person you may contact:

Name Relationship

Street Address City State Zip Code

E-mail address Telephone Number

☐ **No. Please do not contact me in the future.**

Thank you! Please return the completed survey using the stamped envelope provided.



Thank you!

Please return the survey to:

Skin Health Study (Lazovich)

Division of Epidemiology and Community Health

School of Public Health

WBOB

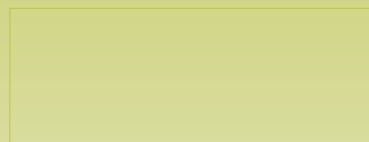
1300 South Second St., Suite 300

Minneapolis, MN 55454-1015



Skin Health Study: **Follow-up Survey**

Survey available online: <http://z.umn.edu/shs2>



Instructions

For each question, please give the answer that seems to best describe how you feel or what your experience has been like. Some of the survey questions may seem the same, but they are all important to answer.

There are questions on both the front and back of each page. Please answer all questions.

I. Your Health Habits

The first questions are about your physical activity, diet, body size, sun protection, and alcohol and smoking habits.

1. Consider a typical 7-day period (a week) in the past month. How many times on average do you do the following kinds of exercise for more than 15 minutes during your free time and for how long per exercise session?

a. **Strenuous activity** (heart beats rapidly, heaving sweating)

Examples: running, jogging, hockey, soccer, squash, cross country, skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling, vigorous aerobic dance classes, heavy weight training

Times per week: _____

Average amount of time per session (minutes): _____

b. **Moderate activity** (not exhausting, light sweating)

Examples: fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing

Times per week: _____

Average amount of time per session (minutes): _____

c. **Mild activity** (minimal effort, no sweating)

Examples: easy walking, yoga, archery, fishing, bowling, lawn bowling, shuffleboard, horseshoes, golf, snowmobiling

Times per week: _____

Average amount of time per session (minutes): _____

Diet Habits

2. How many days per week do you eat at least five (5) servings of fruit and vegetables a day?

One serving = 1 piece of fruit, half a cup of cooked vegetables or one cup of raw leafy vegetables.

- | | |
|---------------------------------|---------------------------------|
| <input type="checkbox"/> 0 days | <input type="checkbox"/> 4 days |
| <input type="checkbox"/> 1 day | <input type="checkbox"/> 5 days |
| <input type="checkbox"/> 2 days | <input type="checkbox"/> 6 days |
| <input type="checkbox"/> 3 days | <input type="checkbox"/> 7 days |

3. Do you currently take a multi-vitamin?

- ☐ No
- ☐ Yes → **3a. On average, how many days per week do you take a multi-vitamin?**
- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

4. Do you currently take vitamin D on a regular basis, either as part of a multi-vitamin, calcium supplement, or as its own pill?

- ☐ No
- ☐ Yes → **4a. On average, how many days per week do you take vitamin D?**
- ☐ 1-2 days
- ☐ 3-4 days
- ☐ 5-6 days
- ☐ 7 days

4b. What is the usual amount you take each day?

- ☐ Less than 400 IU
- ☐ 400 IU
- ☐ 600 IU
- ☐ 800 IU
- ☐ 1000 IU
- ☐ 2000 IU
- ☐ More than 2000 IU
- ☐ Other: _____
- ☐ Unknown

5. How tall are you?

_____ Feet _____ Inches

6. What is your current weight in pounds? _____

Sun Habits

7. In the summer, on average, how many hours are you outside per day between 10am and 4pm...

a. On WEEKDAYS (Monday – Friday)?

- ☐ 0-30 minutes
- ☐ 31-minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

b. On WEEKEND DAYS (Saturday & Sunday)?

- ☐ 0-30 minutes
- ☐ 31-minutes to 1 hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours
- ☐ 5 hours
- ☐ 6 hours

8. In the past 12 months, how many times did you have a red OR painful sunburn that lasted a day or more?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more

9. For the following questions, think about what you typically do when you are outside during the summer on a warm sunny day:

<i>When you are outside during the summer on a warm sunny day, how often do...</i>	Never	Rarely	Sometimes	Often	Always
a. Wear sunscreen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Wear a shirt with sleeves that cover your shoulders?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Wear a hat with a wide brim?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Stay in the shade or under an umbrella?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Spend time in the sun in order to get a tan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. In the last 12 months, have you used a tanning bed or booth with tanning lamps?

☐ No

☐ Yes → 10a. How many times in the last 12 months have you used a tanning bed or booth with tanning lamps? _____

11. In the last 12 months, have you had your skin checked from head to toe by a health professional?

☐ No

☐ Yes

12. In the last 12 months have you or your partner examined your entire body, including your back, for skin cancer?

☐ No

☐ Yes → 12a. How many times in the past 12 months? _____

13. What is the color of your untanned skin?

☐ Very fair

☐ Fair

☐ Olive

☐ Light brown

☐ Dark brown

☐ Very dark

Alcohol Habits

14. During the past 30 days, how many days per month did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage or liquor? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine or a drink with one shot of liquor.

_____ (number of days in past month: 0-30)

15. During the past 30 days, on the days when you drank, about how many drinks did you drink on average?

_____ (number of drinks)

16. Considering all types of alcoholic beverages, how many times during the past 30 days did you have...

... 5 or more drinks on one occasion if you are a man?

... 4 or more drinks on one occasion if you are a woman?

_____ (times in past 30 days)

Smoking Habits

17. Do you currently smoke cigarettes on a regular basis?

☐ No

☐ Yes → 17a. On average, how many packs of cigarettes do you smoke per day?

(1 pack = 20 cigarettes)

☐ Less than ½ pack

☐ ½ pack

☐ 1 pack

☐ 1½ packs

☐ 2 packs

☐ More than 2 packs

18. Do you currently use any of the following tobacco products on a regular basis? Mark all that apply. Mark "none" if you do not use any on a regular basis.

☐ None

☐ Cigars

☐ Pipe tobacco

☐ Chewing tobacco

☐ Dip or snuff

☐ Other → Specify: _____

II. Your Health Habits and Well-Being

The next questions ask about your general physical, emotional, and social well-being.

19. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

20. Compared to 1 year ago, how would you rate your health in general now?

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

21. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	Not limited at all
a. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Climbing <u>several</u> flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Climbing <u>one</u> flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Walking <u>more than a mile</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Walking <u>several blocks</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Walking <u>one block</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your *physical health*?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of *any emotional problems* (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <u>Accomplished less</u> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Did work or other activities <u>less carefully than usual</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

25. How much bodily pain have you had in the past 4 weeks?

- ☐ None
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

26. During the past 4 weeks, how much did pain interfere with your normal work (Including work outside the house and housework)?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

27. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you been very nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Have you felt downhearted and depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Have you been happy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

29. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Emotional Well-Being

The next set of questions will ask you about your emotional well-being.

30. I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

31. I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite as much
- ☐ Only a little
- ☐ Hardly at all

32. I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

33. I can laugh and see the funny side of things:

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

34. Worry thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

35. I feel cheerful:

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

36. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

37. I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

38. I look forward with enjoyment to things:

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

39. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

40. I can enjoy a good book or radio or TV program:

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

41. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

42. I get a sort of frightened feeling like ‘butterflies’ in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

43. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

III. Health Conditions

44. Has a medical doctor or healthcare professional ever told you that you have any of the following?

	Yes	No
a. Heart problems, such as a heart attack, coronary artery disease, congestive heart failure, irregular heartbeat, etc.	<input type="checkbox"/>	<input type="checkbox"/>
b. Hypertension (high blood pressure)	<input type="checkbox"/>	<input type="checkbox"/>
c. Chronic back pain, including sciatica (pain or numbness that travels down your leg to below your knees)	<input type="checkbox"/>	<input type="checkbox"/>
d. Arthritis	<input type="checkbox"/>	<input type="checkbox"/>
e. Stroke, including mini-stroke or blood clots in the brain	<input type="checkbox"/>	<input type="checkbox"/>
f. Severe problems with memory or concentration	<input type="checkbox"/>	<input type="checkbox"/>
g. Asthma, emphysema, or COPD (Chronic Obstructive Pulmonary Disease)	<input type="checkbox"/>	<input type="checkbox"/>
h. Stomach and/or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease	<input type="checkbox"/>	<input type="checkbox"/>
i. Diabetes, high blood sugar, or sugar in urine	<input type="checkbox"/>	<input type="checkbox"/>
j. Depression (feeling sad or blue) that resulted in treatment with medication and/or counseling	<input type="checkbox"/>	<input type="checkbox"/>
k. Anxiety or “nervousness” that resulted in treatment with medication and/or counseling	<input type="checkbox"/>	<input type="checkbox"/>
l. Neuropathy (numbness in both hands or both feet)	<input type="checkbox"/>	<input type="checkbox"/>
m. Melanoma	<input type="checkbox"/>	<input type="checkbox"/>
n. Cancer other than melanoma <i>If yes, provide details:</i> _____	<input type="checkbox"/>	<input type="checkbox"/>
o. Other health conditions <i>If yes, provide details:</i> _____	<input type="checkbox"/>	<input type="checkbox"/>

45. Have any of the following members of your family been diagnosed with melanoma?

	Yes	No	Not Applicable
a. Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Brother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Grandchildren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IV. Work and Insurance

The next questions are about work and insurance.

46. What is your **CURRENT** employment status? If more than one category applies, please choose the one that best describes your current employment status.

- | | |
|----------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Paid full-time employment | <input type="checkbox"/> Unemployed, looking for work |
| <input type="checkbox"/> Paid part-time employment | <input type="checkbox"/> Unemployed, not looking for work |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Not employed – disabled |
| <input type="checkbox"/> Volunteer | <input type="checkbox"/> Retired, not working |
| <input type="checkbox"/> Homemaker | <input type="checkbox"/> Student, not working |

47. During the past 12 months, about how many days did you miss work at your job or business because of illness (do not include maternity leave)? _____ days

48. During the past 12 months, about how many days did illness keep you in bed more than half of the day (include days while an overnight patient in a hospital)? _____ days

49. Do you currently have health insurance coverage?

- ☐ No
- ☐ Yes → **Continue below**

49a. Indicate the source of your health insurance (check all that apply)

- ☐ Your current or former employer
- ☐ A policy you purchased directly (not through your employer or union)
- ☐ Your union
- ☐ Military (Tricare, Tristar, Champus)
- ☐ Spouse/Partner's employer
- ☐ Another family member's health plan (not spouse/partner)
- ☐ Medicare
- ☐ Medicaid
- ☐ Other: _____

50. Do you have a life insurance policy?

- ☐ Yes
- ☐ No
- ☐ Unsure

V. Your Background

51. What is your current age? _____

52. What is your sex?

- ☐ Male
- ☐ Female

53. What is your race? (1 or more categories may be selected)

- | | |
|-----------------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> White | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Other Asian |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Native Hawaiian |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Guamanian or Chamorro |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Japanese | <input type="checkbox"/> Other Pacific Islander |

54. Are you Hispanic, Latino/a, or of Spanish origin? (1 or more categories may be selected)

- ☐ No, not of Hispanic, Latino/a, Spanish origin
- ☐ Yes, Mexican, Mexican American, Chicano/a
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban origin

55. What is the highest level of schooling you have completed?

- ☐ Less than high school
- ☐ High school graduate
- ☐ Vocational or business school or AA degree
- ☐ Some college
- ☐ College or university graduate (bachelor's degree)
- ☐ Graduate or professional training (graduate degree)

***** CONTINUE TO NEXT PAGE *****

56. What is your marital status?

- | | |
|----------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Never married | <input type="checkbox"/> Widowed |
| <input type="checkbox"/> Married / Partnered | <input type="checkbox"/> Divorced |

57. What is your annual household income?

- | | |
|-----------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$100,000 to \$149,999 |
| <input type="checkbox"/> \$20,000 to \$49,999 | <input type="checkbox"/> \$150,000 to \$199,999 |
| <input type="checkbox"/> \$50,000 to \$74,999 | <input type="checkbox"/> \$200,00 or more |
| <input type="checkbox"/> \$75,000 to \$99,999 | <input type="checkbox"/> Prefer not to say |

Future research

We are interested in conducting new research about melanoma that builds on the information that you have so generously shared with us. Below, we ask for your permission to continue to work with us on related research. Thank you for your consideration!

Request permission to contact you in the future:

Would you give us permission to contact you in the future for new research projects? If yes, could you provide the name of a contact person who will know of your whereabouts in the event that you move?

- ☐ **Yes, I give my permission.**

My contact Information:

Email address: _____ Telephone Number: _____

Alternative Person you may contact:

_____	_____	_____	_____
Name		Relationship	
_____	_____	_____	_____
Street Address	City	State	Zip Code
_____	_____	_____	_____
E-mail address		Telephone Number	

- ☐ **No. Please do not contact me in the future.**

Thank You. Please return the completed survey using the stamped envelope provided.



Thank you!

Please return the survey to:

Skin Health Study (Lazovich)

Division of Epidemiology and Community Health

School of Public Health

WBOB

1300 South Second St., Suite 300

Minneapolis, MN 55454-1015



UNIVERSITY OF MINNESOTA

Appendix G. Physician Contact Materials

UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Division of Epidemiology
& Community Health
School of Public Health*

*Suite 300
1300 S. 2nd Street
Minneapolis, MN 55454-1025
Phone: 612-624-1818
Fax: 612-624-0315*

Fax Cover Sheet

Send to: «Clinic_Name»	From: Dr. DeAnn Lazovich
Attention: Dr. «Doc_CURRENT_fname» «Doc_CURRENT_lname»	Date: October 3, 2015
Fax Number: «Clinic_fax»	Phone Number: (612) 625-4542
Total Pages Including Cover:	Return Fax Number: <u>(612) 624-0315</u>

«Fax_Cover_Page_Notes»

CONFIDENTIALITY NOTICE: The information in this email message, including any attachments, is confidential and intended only for the recipient(s). This message may be subject to confidentiality protections. If you are not the intended recipient(s), you may not review, copy, or distribute this message. If you received this message in error, please contact the sender by reply email or call 612-624-1818 to report error and delete all copies of this original email

UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Division of Epidemiology
& Community Health
School of Public Health*

*1300 S. 2nd Street, Suite 300
Minneapolis, MN 55454-1025
Fax: 612-624-0315*

October 3, 2015

Dr. «Doc_CURRENT_fname» «Doc_CURRENT_lname»
«Clinic_Name»
«Clinic_address»
«Clinic_city», MN, «Clinic_zip»

Dear Dr. «Doc_CURRENT_lname»:

With your permission, one or more of your patients diagnosed with melanoma participated in the Skin Health Study conducted between December 2004 and March 2009. This research study, funded by the National Institutes of Health, was designed to identify new risk factors for melanoma, e.g., indoor tanning. We found that use of indoor tanning increased risk of melanoma by 74%, the risk increased with greater frequency of indoor tanning, and that no type of tanning device was safe. These results have informed policies that limit indoor tanning use, especially for minors, here and abroad. Your patient's participation was critical to the success of our research and contributed to improving the public's health.

With funding from the Masonic Cancer Center at the University of Minnesota, we have now launched a new study to follow patients who were previously in the Skin Health Study. In the new study, Skin Health Study participants will be asked to:

- Complete an online survey about quality of life and experience living with a melanoma diagnosis to inform new strategies to improve survivorship;
- Provide permission to obtain medical records related to their diagnosis and treatment to understand the effect of treatment (if any) on melanoma survivorship;
- Provide permission to obtain a sample of their original tumor specimen to support studies for the molecular characterization of tumors and prognosis in a large population-based sample.

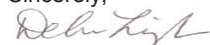
The University of Minnesota's Human Subjects Committee approved this proposed expansion of our original study. The Minnesota Commissioner of Health, upon recommendation from the scientific review committee of the Minnesota Cancer Surveillance System, has also approved the study.

The Minnesota Cancer Surveillance System at the Minnesota Department of Health has determined that we are required by law to ask your permission before re-contacting your patients who participated in the Skin Health Study. Enclosed is a separate consent form for each of your patients. Please note that it is not required that you contact your patients. Your consent does not obligate your patient(s) to participate; it only allows us to contact patients to invite their participation. If you have no objection, we will send your patients a letter with details about the study. Their participation is completely voluntary.

Please indicate your decision regarding patient contact by checking a box and signing each consent form and returning it to us via fax (612 624-0315).

If you have any questions or you would like more information, please feel free to contact me (612 626-9099 or lazov001@umn.edu). Thank you for your time and attention.

Sincerely,



DeAnn Lazovich, Ph.D.
Associate Professor and Principal Investigator
Division of Epidemiology and Community Health
University of Minnesota

«Doc_ID»

Skin Health Study Expansion Research Project

Physician Consent Form

INSTRUCTIONS: Please complete this form and fax to DeAnn Lazovich, Ph.D. at (612) 624-0315. Thank you!

Patient Information

Name: «Pt_fname» «Pt_mname» «Pt_lname» Study ID: Pt.(«IDBase») Dr.(«Doc_ID»)
Date of Birth: «Pt_DOB» Sex: «Pt_Sex»
Last known address: «Pt_Addr»
City: «Pt_city» State: «Pt_State» Zip Code: «Pt_Zip»

If Patient is STILL under your care, please check one of the following:

- ☐ I GIVE MY CONSENT to allow Dr. Lazovich, as a representative of the Commissioner of Health, to contact this patient.
- ☐ I DO NOT GIVE MY CONSENT to allow this patient to be contacted.

If Patient is NO LONGER under your care, please complete this section

- ☐ Patient is under the care of another physician who is better able to make a decision about the appropriateness of contacting this patient.
- Name of Physician: _____
Address: _____
City: _____ State: _____ Zip: _____
- ☐ Patient is deceased.
We would like to contact next of kin for permission to obtain a sample of the patient's tumor, if available. Please provide name and contact information for next of kin, if known.
- Name of next of kin: _____
Address: _____
City: _____ State: _____ Zip: _____
- ☐ I am no longer caring for this patient and have no knowledge of this patient's status or current provider.

Physician Signature: _____ **Date:** _____

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Division of Epidemiology
& Community Health
School of Public Health

1300 S. 2nd Street, Suite 300
Minneapolis, MN 55454-1025
Fax: 612-624-0315

October 3, 2015

Dr. «Doc_CURRENT_fname» «Doc_CURRENT_lname»
«Clinic_Name»
«Clinic_address»
«Clinic_city», MN, «Clinic_zip»

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- Provide permission to obtain medical records related to their diagnosis and treatment to understand the effect of treatment (if any) on melanoma survivorship;
- Provide permission to obtain a sample of their original tumor specimen to support studies for the molecular characterization of tumors and prognosis in a large population-based sample.

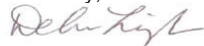
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Please indicate your decision regarding patient contact by checking a box and signing each consent form and returning it to us via fax (612 624-0315). **If we do not hear from you by «Deadline_for_2nd_Return», we will assume that we have your consent to contact these patients.**

If you have any questions or you would like more information, please feel free to contact me (612 626-9099 or lazov001@umn.edu). Thank you for your time and attention.

Sincerely,



DeAnn Lazovich, Ph.D.
Associate Professor and Principal Investigator
Division of Epidemiology and Community Health
University of Minnesota

«Doc_ID»

Appendix H. Initial Mailing Materials

TYPE DATE HERE

«First_Name» «Last_Name»

«Address»

«City», «State» «Zip_Code»

Dear «First_Name»,

Between 2004 and 2009, you participated in our Skin Health Study to help us learn more about the causes of melanoma. Thanks to your time and willingness to share details about yourself, we learned new information about melanoma that is now making a difference in the lives of others.

I am writing now to ask for your help in improving our understanding of life **after** a melanoma diagnosis. The best way we know to do this is by asking you to complete a one-time survey that we have made available to you online. The survey asks about your melanoma diagnosis and treatment, current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. We are inviting everyone in the Skin Health Study to take part in this new research study, which is funded by the University of Minnesota.

To take our online survey, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs1>

When prompted, enter your study ID: **«ID»**

If taking the survey on a computer is hard for you, we can send you a paper copy if you let us know by email (shs@umn.edu) or telephone (612-624-3056).

Your participation is completely voluntary and the information you provide is strictly confidential. The online survey uses a secure web interface to protect the data that you enter. If you have any questions or concerns, or if you are sure you do not wish to participate, please feel free to contact us at any time.

By sharing your experiences with us, you will be adding to our understanding of this cancer to help others better cope with a melanoma diagnosis. *Your participation has already and will continue to make a difference!*

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

P.S. We have enclosed a small token of appreciation as a way of saying thanks for taking the time to complete the survey!

CONSENT FORM
SKIN HEALTH FOLLOW-UP STUDY
Online Survey

INTRODUCTION

You are invited to be in a scientific research study that is being conducted by Dr. DeAnn Lazovich at the University of Minnesota School of Public Health. The purpose of this study is to learn more about the experiences of people with melanoma after diagnosis compared to people without a melanoma diagnosis. The study is funded by the University of Minnesota. You were selected because you previously participated in the Skin Health Study between 2004 and 2009.

STUDY PROCEDURES

If you choose to be in the study, we will ask you to take a one-time online survey. The survey asks about your diagnosis and treatment, current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. The survey will take between 20 and 40 minutes, depending on your medical history.

CONFIDENTIALITY

The records of this study will be kept private and confidential. In any report we might publish, we will not include any information that will make it possible to identify a participant. Every precaution is taken to make sure that all data are kept safe and secure. The online survey uses a secure web interface to protect the data that you enter. Only researchers involved in this project will have access to these data files.

RISKS AND BENEFITS

There are no known risks, except for possible breach of confidentiality. However we will take every precaution to keep your study information confidential. Although there are no direct benefits to you from participating in this study, the information you provide may help us learn about ways to assist persons who have been diagnosed with melanoma.

VOLUNTARY NATURE

Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

WHOM TO CONTACT

If you have any questions about the study, you may contact Dr. Lazovich or her research staff by email (melanoma@umn.edu) or by phone (612 624-3056). If you have questions or concerns regarding this study and would like to talk to someone other than the researcher (s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at Fairview Research Administration, 2433 Energy Park Drive, St. Paul, MN, 55108.

Please See Reverse Side of Page

STATEMENT OF CONSENT:

I have read the above information. I have had the opportunity to ask questions and receive answers.
I agree to participate in the study.

When you start the online survey you will be asked at that time if you agree to participate in this study. Please keep this Consent Form for your records.

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

Between 2004 and 2009, you participated in our Skin Health Study to help us learn more about the causes of melanoma, a serious form of skin cancer. Thanks to your time and willingness to share details about yourself, we learned new information about melanoma that is now making a difference in the lives of others.

I am writing now to ask your help in improving our understanding of life after a melanoma diagnosis. The best way we know to do this is by asking you to complete a one-time survey that we have made available to you online. The survey asks about your current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. We are inviting everyone in the Skin Health Study to take part in this new research study, which is funded by the University of Minnesota.

*For scientific reasons, it is very important that we include you in this study even if you **have never** been diagnosed with melanoma.*

To take our online survey, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs2>

When prompted, enter your study ID: **«ID»**

If taking the survey on a computer is hard for you, we can send you a paper copy, if you let us know by email (shs@umn.edu) or telephone (612-624-3056).

Your participation is completely voluntary and the information you provide is strictly confidential. The online survey uses a secure web interface to protect the data that you enter. If you have any questions or concerns, or if you are sure you do not wish to participate, please feel free to contact us at any time.

By sharing your experiences with us as someone who does not have melanoma, you will be adding to our understanding of this cancer to help others better cope with a melanoma diagnosis. *Your participation has already and will continue to make a difference!*

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

P.S. We have enclosed a small token of appreciation as a way of saying thanks for taking the time to complete the survey!

**CONSENT FORM
SKIN HEALTH FOLLOW-UP STUDY
Online Survey**

INTRODUCTION

You are invited to be in a scientific research study that is being conducted by Dr. DeAnn Lazovich at the University of Minnesota School of Public Health. The purpose of this study is to learn more about the experiences of people with melanoma after diagnosis compared to people without a melanoma diagnosis. The study is funded by the University of Minnesota. You were selected because you previously participated in the Skin Health Study between 2004 and 2009.

STUDY PROCEDURES

If you choose to be in the study, we will ask you to take a one-time online survey. The survey asks about your current health, health habits such as physical activity and sun protection, physical, emotional and social well-being, employment and insurance. The survey will take between 15 and 25 minutes.

CONFIDENTIALITY

The records of this study will be kept private and confidential. In any report we might publish, we will not include any information that will make it possible to identify a participant. Every precaution is taken to make sure that all data are kept safe and secure. The online survey uses a secure web interface to protect the data that you enter. Only researchers involved in this project will have access to these data files.

RISKS AND BENEFITS

There are no known risks, except for possible breach of confidentiality. However we will take every precaution to keep your study information confidential. Although there are no direct benefits to you from participating in this study, the information you provide may help us learn about ways to assist persons who have been diagnosed with melanoma.

VOLUNTARY NATURE

Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

WHOM TO CONTACT

If you have any questions about the study, you may contact Dr. Lazovich or her research staff by email (melanoma@umn.edu) or by phone (612 624-3056). If you have questions or concerns regarding this study and would like to talk to someone other than the researcher (s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at Fairview Research Administration, 2433 Energy Park Drive, St. Paul, MN, 55108.

Please See Reverse Side of Page

STATEMENT OF CONSENT:

I have read the above information. I have had the opportunity to ask questions and receive answers.
I agree to participate in the study.

When you start the online survey you will be asked at that time if you agree to participate in this study. Please keep this Consent Form for your records.

Helpful Tips for Taking the Online Survey

Before linking to the online survey

- Please use a computer, NOT a smartphone or tablet
- The best browsers to use are Mozilla Firefox, Safari, and Google Chrome.

While taking the survey online

- To make the survey easier to read, you can change the font size. In the upper right hand corner of the screen, click on 'resize fonts' to increase or decrease font size. However, changing the font size may change the survey format.
- At the bottom of each survey page, you have the option to go back to the 'previous page', go to the 'next page' or 'save & return later'. Most of the time, these instructions can be seen on your screen along with the questions on that page. Occasionally, you may need to scroll down to answer all questions and go to the next page.
- Use the 'reset' button on the right hand side of each question to clear your answer.
- If you skip a question by mistake, the computer will remind you before it allows you to go to the next page. Questions that show in red print "must provide value" will need to be answered before you are able to move on.

If you want to stop and finish the survey at a later time

- The survey will give you a validation code and instructions for returning to the survey at a later time.
- Write down validation code here:

To continue and finish the survey

- Click on Returning in upper right had corner and enter your validation code:



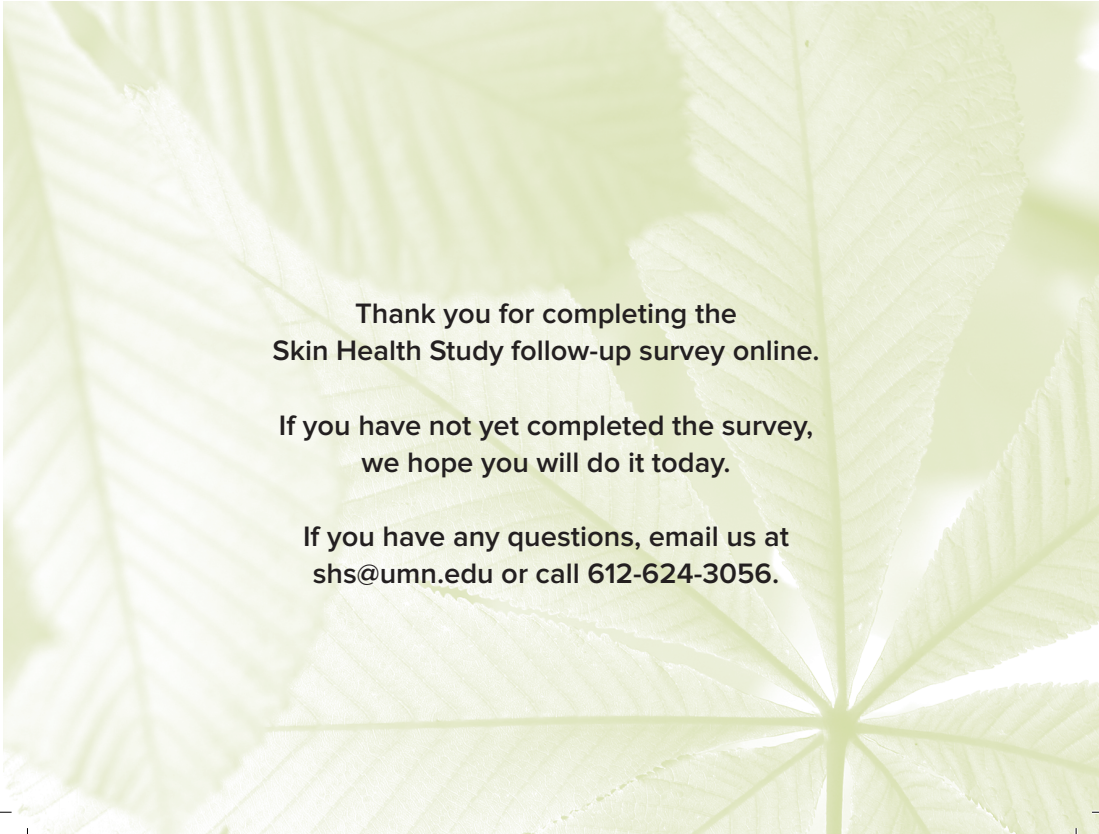
*Questions or problems? Contact us at
shs@umn.edu or 612-624-3056*

Appendix I. Thank You Card

UNIVERSITY OF MINNESOTA 



Thank you!



**Thank you for completing the
Skin Health Study follow-up survey online.**

**If you have not yet completed the survey,
we hope you will do it today.**

**If you have any questions, email us at
shs@umn.edu or call 612-624-3056.**

Appendix J. Reminder Mailing Letters

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

About three weeks ago, we sent you a survey request asking for your help in improving our understanding of life **after** a melanoma diagnosis. To the best of our knowledge, we have not yet received your responses. Our hope is to learn how to help others cope with a melanoma diagnosis if ever faced with that diagnosis.

We are writing again because of the importance that your responses have for helping us get accurate results. It is only by hearing from nearly everyone who was part of the Skin Health Study that we can be sure that the results truly represent the experience of persons who have had melanoma. Thus, we hope that you will fill out the survey soon.

You have two options for taking the survey. You can complete the enclosed survey and return to us in the postage-paid envelope provided. Or you can take the survey online. If you took the survey online since the date of this letter, we thank you and please disregard this mailing.

If you choose to take our online survey, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs1>

When prompted, enter your study ID: **«ID»**

Your participation is completely voluntary and the information you provide is strictly confidential. The online survey uses a secure web interface to protect the data that you enter. If you have any questions, concerns, or further issues, please contact us by email (shs@umn.edu) or telephone (612-624-3056).

Thank you so much for your help with this important health concern.

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

Our records show that you started the online Skin Health Study follow-up survey but did not have a chance to finish it.

If you were unable to finish due to technical or computer problems with the online survey, please email or call us and we will be happy to help you. If you did not finish for other reasons and wish to do so, the information you need is provided below.

To return to your online survey, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs1>

Then enter your validation code. Your validation Code is: _____.

You will be directed to where you left off.

Your participation is completely voluntary and the information you provide is strictly confidential. The online survey uses a secure web interface to protect the data that you enter.

If you have any questions, concerns, or further issues or would prefer a paper survey, please contact us by email (shs@umn.edu) or by telephone (612-624-3056).

We hope you will choose to complete the survey. Your contributions will help researchers understand the unique experience of persons who have had melanoma.

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

About three weeks ago, we sent you a survey request asking for your help in improving our understanding of life after a melanoma diagnosis. To the best of our knowledge, we have not yet received your responses. Our hope is to learn from **both persons with and without melanoma** how to help others cope with a melanoma diagnosis if ever faced with that diagnosis.

We are writing again because of the importance that your responses have for helping us get accurate results. It is only by hearing from nearly everyone who was part of the Skin Health Study that we can be sure that the results truly represent the experience of persons who have and have not had melanoma. Thus, we hope that you will fill out the survey soon.

You have two options for taking the survey. You can complete the enclosed survey and return to us in the postage-paid envelope provided. Or you can take the survey online. If you took the survey online since the date of this letter, we thank you and please disregard this mailing.

If you choose to take our online survey, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs2>

When prompted, enter your study ID: **«ID»**

Your participation is completely voluntary and the information you provide is strictly confidential. The online survey uses a secure web interface to protect the data that you enter. If you have any questions, concerns, or further issues, please contact us by email (shs@umn.edu) or telephone (612-624-3056).

Thank you so much for your help with this important health concern.

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

Our records show that you started the online Skin Health Study follow-up survey but did not have a chance to finish it.

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We hope you will choose to complete the survey. Your contributions will help researchers understand the unique experience of persons who have had melanoma.

Many thanks,



DeAnn Lazovich, Ph.D., Associate Professor
Principal Investigator, Skin Health Study
University of Minnesota
School of Public Health

Appendix K. Final Reminder Letters

TYPE DATE HERE

«First_Name» «Last_Name»
«Address»
«City», «State» «Zip_Code»

Dear «First_Name»,

In recent weeks, our research team has asked you, as a previous participant in the Skin Health Study, to help us improve our understanding of life **after** a melanoma diagnosis. We plan to start summarizing results soon, so we hope that all questionnaires will be completed by the middle of October.

You can help us by EITHER 1) filling out the questionnaire we mailed to your household about 1-2 weeks ago and returning it in the stamped envelope, OR 2) by completing the questionnaire online.

To complete the questionnaire online, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs1>

Next enter your study ID: «ID»

Our hope from this research is to learn how to help others cope with melanoma if ever faced with that diagnosis.

This is the last contact we will be sending you about this survey, as we are bringing this phase of the project to a close. If you need another paper copy of the survey, or have any questions about the study, please contact us by email at shs@umn.edu or by phone at 612-624-3056.

Many thanks for considering our request.

Respectfully and with appreciation,



DeAnn Lazovich, Ph.D.
Associate Professor

TYPE DATE HERE

«First_Name» «Last_Name»

«Address»

«City», «State» «Zip_Code»

Dear «First_Name»,

In recent weeks, our research team has asked you, as a previous participant in the Skin Health Study, to help us learn how to help others cope with melanoma if ever faced with that diagnosis. For scientific reasons, it is very important that we include you in this study even if you **have never** been diagnosed with melanoma. We plan to start summarizing results soon, so we hope that all questionnaires will be completed by the middle of October.

You can help us by EITHER 1) filling out the questionnaire we mailed to your household about 1-2 weeks ago and returning it in the stamped envelope, OR 2) by completing the questionnaire online.

To complete the questionnaire online, first enter this address into your Internet browser's address bar:

<http://z.umn.edu/shs2>

Next enter your study ID: «ID»

This is the last contact we will be sending you about this survey, as we are bringing this phase of the project to a close. If you need another paper copy of the survey or have any questions about the study, please contact us by email at shs@umn.edu or by phone at 612-624-3056.

Many thanks for considering our request.

Respectfully and with appreciation,



DeAnn Lazovich, Ph.D.
Associate Professor